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Seeing the Wood for the Trees

Carer-related research and knowledge: A scoping review

Melanie Henwood, Mary Larkin and Alisoun Milne
Submitted to NIHR SSCR May 2017



Melanie Henwood Associates
Health & Social Care Consultancy



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Executive Summary

1. An NIHR-SSCR funded scoping review was undertaken on carer-related evidence and knowledge between April and December 2016. The objectives of the review had two complementary purposes: first, to provide a unique and comprehensive detailed mapping of what is known about carers and caring, and second in partnership with SCIE to provide a platform for a dynamic, searchable digital resource to be readily accessible to a full range of interested stakeholders.
2. While there is a great deal of research and evidence available about carers, it is generally fragmented, located in a variety of places and difficult to access. For the first time, the scoping review aims – uniquely - to bring together the knowledge in one place and for it to be accessible via a single portal.
3. The timing of the review has regard to the tasks associated with the implementation of the Care Act 2014, and the new duties it introduces in giving carers parity of esteem, strengthening carers' rights to an assessment and to information and advice, and requiring local councils to meet carers' eligible needs.
4. In this report we explore the background to the review in terms of the research and policy context before introducing the scoping review. The origins of academic research interest in carers in the 1980s and 1990s were largely based in sociological and feminist literature that identified the gendered nature of caring. This approach was also characterised by a conceptual separation of carers and cared for people, with care seen largely as the instrumental support of one person 'doing care' to another. Critical response to this model came in part from disabled people who rejected the passive recipient role and instead drew attention both to interdependence and – at times – conflicting interests.
5. The understanding of carers in the emergence of policy is also explored, including the implications of seeing carers as resources, or as entitled to support in their own right. Such considerations continue to be relevant in the context of the implementation of the 2014 Care Act and the stated objective of giving carers parity of esteem.
6. The review was undertaken by searching 10 key electronic bibliographic databases supplemented by additional web searches. In addition to mainstream academic materials, the review was concerned to identify and capture wider resources, knowledge and grey literature. All resources were organised using EndNote, and a

library of 3,434 items was generated with materials classified under four categories and sixty-two themes.

7. Analysis of the resources adopts a selective thematic approach, highlighting the themes of particular significance in terms of frequency and attention. Caring is extremely diverse and involves all sections and age groups of the population; people are likely to experience one or more periods of caregiving over the course of a lifetime.
8. There are both similarities and differences in the experiences of carers, but all caring takes place within a relationship, and each relationship is unique. Attention to both parties in a dyad is essential in understanding where interests are shared and where they diverge.
9. Knowledge about 'hard to reach' groups – notably BAME and LGBT carers – remains relatively sparse. The profile of young carers has grown considerably in recent years, but they remain a small proportion of carers overall. Older carers are of increasing importance, particularly in providing care for an elderly spouse or partner; such carers are the most heavily involved in caregiving but remain relatively invisible both in policy and research terms.
10. The impact of caring is multi-faceted and much of this is referred to within a 'burden of care' discourse that can be seen as pejorative, and which fails to take account of the simultaneous reported satisfactions of caring, or of the complexities and interdependencies within a caring relationship. How carers cope, and what strategies are effective in enabling them to do so are attracting increasing attention.
11. Many carers face multiple and at times competing demands, not least those trying to balance caring responsibilities with other family demands and paid employment. The business case for increasing flexibility to accommodate working carers is increasingly recognised, but different strategies are required in different employment contexts.
12. Much of the knowledge about carers and their circumstances relates to their characteristics, their lived experience and the nature and duration of their caregiving; relatively less is known about the effectiveness of interventions to support carers. Some of the findings – such as on respite care – are contradictory. The evidence in support of some psychosocial interventions seems to be the strongest, but it would appear there is no 'quick fix'. Indeed, even where interventions do not appear successful against specified outcome criteria, carers may report positive subjective benefit from the process and experience of interventions.

13. The scoping review is intended to inform policy, practice and research. However, it does not offer an oracle or an index of solutions. Evidence is complicated and nuanced and almost all the conclusions need to be seen within specific caveats. However, as the review highlights, the current state of knowledge shines a light on areas that require attention and priority.
14. Conclusions about the current state of knowledge need also to inform future research and commissioning. Deficits in knowledge need to be addressed, with priority given to expanding the evidence base through using appropriate methodologies and models. We offer a model that attempts to integrate previously separate research paradigms; which acknowledges and incorporates the complexity of knowledge about care and care giving, and that seeks to understand the interdependencies inherent in caring relationships. Finally, much of the research evidence is cross-sectional and offers a 'snapshot' of a point in time; the value of developing robust longitudinal research in caring has long been recognised, and this review once again strengthens that argument.
15. For the first time, this review has used a scoping methodology to identify and classify the wide and diverse carer-related knowledge base. It is not offered as a definitive or final overview of this territory, which is dynamic and evolving. However, we have created a unique foundation for a resource that can be expanded and developed, lending itself to further analysis and exploration.

1 Introduction

- 1.1 The terms 'carer' and 'caregiver' are used throughout this review to refer to people who provide care and support, on an unpaid basis to people (children and adults) who are sick, disabled, frail or elderly, and which enables them to live as independently as possible in their own homes and in the community. In earlier years, the term 'informal carer' was often used to describe this type of carer, but 'carer' alone is now in more frequent usage (and 'caregiver' is the preferred term in the USA). It is important, however, to distinguish carers from people who are employed in social care (as care assistants, home care workers etc.) and who are paid to undertake personal care and support. While care workers are vital to enabling people to maintain their independence, they are part of a care economy and the issues surrounding their employment (terms and conditions, training and qualifications, regulation etc.) are of a different order to those relating to unpaid carers.
- 1.2 In using these terms, we recognise that they are not without controversy. Molyneaux et al, for example, have presented a critique on the adoption of the term 'carer', concluding that it is "ineffective and that its continued use should be reconsidered" (Lloyd, 2006; Molyneaux, Butchard, Simpson, & Murray, 2011). Lloyd has similarly drawn attention to the risks and limitations of reserving the term 'carer' to refer exclusively to unpaid carers (Lloyd, 2006). We recognise that caring is often a reciprocal relationship, and indeed this is a theme which runs throughout this report. We also accept that caring needs to be viewed through the lens of different relationships (such as parent, spouse, child etc.). However, the suggestion that in place of the term 'carer' "*descriptions of the caring relationship*" would be both more useful and acceptable to those concerned is one perspective among many, and there is no consensus about the adoption of an alternative lexicon. Our use of carer terminology does not imply lack of awareness of the contested nature of the word, nor of its lack of precision.
- 1.3 As we will explore in this report, there is growing interest in carers and caregiving in national and international research, and in a wider public discourse. An extensive body of research and knowledge has accrued since the 1980s, and particularly so in more recent years. The nature of this knowledge is diverse, and while it strongly features academic papers and research articles, it also includes: a disparate collection of project reports; lobbying and campaigning materials from interest groups; conference papers and proceedings; national and local policy and practice documents, guidance and strategies; data sets and statistical publications; digital resources and interactive

media. These materials are generated by a similar range of individuals, organisations, research centres and departments; third sector bodies and government departments and quangos. This richness and diversity is to be celebrated; however, precisely because of the disparate and wide-ranging nature of this knowledge, it is highly fragmented and compartmentalised. There has not previously been an attempt to comprehensively map and analyse this body of knowledge, or to delineate the contours of this landscape. This is precisely the focus of the present scoping review.

- 1.4 Carers are typically – although not always – family members, most often caring for a parent/parent-in-law; a spouse or partner; a child, sibling or other relative. Research into carers and knowledge about the caring life cycle has developed significantly in the past three decades. At the same time, carers have increasingly been acknowledged within policy and practice, both in national legislation and local implementation. It should not be assumed that this greater ‘carer awareness’ means that carers are therefore fully recognised and well supported, and particular groups of carers (notably older carers and also young carers) are often overlooked and poorly supported (Carers UK, 2015b)
- 1.5 The 2011 population census indicated that 6.5 million people in the UK are carers, an increase of 11% since the previous census of 2001 (Carers UK, 2015a). There is considerable ‘churn’ in the carer population, and each year more than 2.1 million people become carers and a similar number end their caring responsibilities (Hirst, 2014). It is estimated that 3 in 5 people will be carers at some point in their lives.
- 1.6 Around 4 million carers are caring for less than 20 hours each week, but 1.4 million people are providing at least 50 hours a week. The middle aged (55-64) are the most likely to be carers, and this is true of almost one in five of the age group (18%) (Health and Social Care Information Centre, 2010). More than 40% of carers are aged 45-65, but a quarter (1.3 million people) are aged at least 65. Carers are engaged in a wide variety of help and support, from companionship and ‘keeping an eye’ on someone, to intensive personal and physical care. People caring for longer hours each week (typically those in the same household) are the most likely to be providing personal care.
- 1.7 Carers are most likely to care for a close family member such as a parent (33%), followed by a spouse or partner (26%). However, this differs by age and older carers are the most likely to be caring for a spouse or partner (58%), while the middle aged are more likely to care for a parent or in-law (50%). Women are more likely to be

carers than men (58% of carers are female and 42% male), but among the oldest age groups (aged over 85), almost 60% of carers are men.

- 1.8 This scoping review has distinctive objectives. For the first time ever a review has been designed to scope out and synthesise what is known about carers, bringing together disparate sources and materials to provide a unique and comprehensive review of carer-related knowledge and evidence. This is intended to inform and provide a resource for: researchers (and research funders); national and local policy development and practice, as well as for carers themselves, and for frontline support workers. Potentially this is a very large remit. We are focusing on research evidence, but also on wider knowledge, or what is often termed as 'grey literature'. Understanding what is known about carers is important for two major reasons:
- It enables the research community to overcome the fragmentation of existing knowledge and to look comprehensively to identify areas where evidence is thin or lacking and for future research to be targeted accordingly; and to avoid duplication of research investment.
 - It is vital that people who are most closely involved in policy and practice that impacts on carers are informed and knowledgeable and understand the implications of evidence for arranging the most appropriate support for carers.
- 1.9 The project had two primary aims. First, to comprehensively scope existing carer-related research evidence and knowledge, and thereby to provide a comprehensive and informed synthesis of what is known about carers, and to reflect on the range, type and nature of evidence. The resulting scoping review will support the second aim which is to enable an accessible digital evidence resource to be developed in partnership with and hosted by SCIE, that can be readily updated and maintained. Before we introduce our approach, methodology and analysis, we begin by setting the scene and exploring the background and context to the emergence of carers both as a focus of research, and also as the subject of legislation, policy and practice.
- 1.10 Implementation of Part 1 of the Care Act 2014 took effect in April 2015. This is a landmark piece of legislation for carers and integral to its effective implementation is synthesis of, and increased access, to carer-related information and knowledge for carers, people who use services and social care workers (ADASS, 2015; Carers UK, 2014).

- 1.11 The Care Act 2014 substantially replaces and consolidates existing legislation for carers and those they support. It introduces parity of esteem between carers and service users, strengthens carers' rights to an assessment of need and places a new duty on local authorities to fund support for carers' 'eligible needs'. Furthermore, the Care Act (2014) legally entitles carers to information and advice (HM Government, 2014; Larkin & Mitchell, 2016). The implications of the Act for enhancement of social care practice are significant: relevant stakeholders include: commissioners, care workers, social workers; carers themselves; carers' organisations, carers' support workers, people who use services and personal assistants.
- 1.12 The rise of carers as a focus of research and analysis paralleled (and arguably led) the growing recognition of carers within public policy. In Britain that development can be tracked from the mid-1980s. The review focuses on knowledge and resources produced since 2000, however, these need to be understood against the background of earlier research and analysis. In the UK much of the early theorising about caring came from academic feminist studies and sociological perspectives that identified the gendered nature of caring, associating the role of carer with women's social identity and their unpaid labour within the home (Finch & Groves, 1980, 1983; Graham, 1983; Ungerson, 1987; Walmsley, 1993). Indeed, some of the earliest studies of the experience of caring and nature of support for carers were undertaken by the Equal Opportunities Commission (Equal Opportunities Commission, 1980, 1984).
- 1.13 In the 1980s much of the focus of research conceptualised care as the instrumental support of one person 'doing care' to another, with the 'carer' and 'cared for' as a dichotomised pairing. This model came to be challenged not only because it was seen as a white middle-class perspective which failed to recognise class and race dimensions (Walmsley, 1993), but also because it addressed only one side of the care equation and tended to portray disabled people as passive recipients, and whose interests – particularly in terms of maintaining independent lives in the community – were depicted as antithetical to those of feminists (Morris, 1991).
- 1.14 Since the 1990s the critique – not least from disabled people - that caring may be characterised by interdependence, and that the boundary between carer and cared for can be fluid and shifting, has attracted increasing recognition and is a recurrent theme in this review (Larkin & Milne, 2013).
- 1.15 Twigg drew attention to the 'ambiguous position' occupied by carers within the social care system which, she argued, creates confusion in the relationship. Her analysis

identified three dominant practice models: carers as resources; carers as co-workers; and carers as co-clients (Twigg, 1989). This provided the foundation for the subsequent widely cited typology of caring with the addition of a fourth model of 'superseded carers' (Twigg & Atkin, 1995). Twigg and Atkin saw the dominant model operating in frontline practice as that of carers as a resource in which they provide the taken-for-granted support for a person, and where the interests of carers themselves are marginal. Where carers are perceived as co-workers, there is recognition of their contribution as partners in care, and of the need to maintain their well-being, but only in instrumental terms to enable the continuation of their caring. Where carers are co-clients they are seen as needing support in their own right, while in the final model of superseded carers, support is provided which can mean that the carer's role is no longer necessary.

- 1.16 The assumptions which lie behind each of the categories, and the tensions which they reveal in locating carers as part of the care system continue to resonate (Manthorpe, Illife, & Alison, 2003), and we return to some of these issues at the end of the review.
- 1.17 Since the 1990s there has been increasing recognition in policy and service development for ever increasing numbers of family carers across the UK. Prior to this time political and policy references to the role of families and communities were highly general in nature and largely expressed in terms that emphasised the duty of families rather than acknowledging the needs of carers. The rights of carers were first given legislative effect in the 1995 Carers (Recognition and Services) Act and in the subsequent development since 1999 of the National Carers Strategy supported by successive governments and providing the strategic vision for recognising, valuing and supporting carers. Some key benchmarks in the emergence of carer policy can be identified and are summarised in Table 1.1.
- 1.18 To date, there have been a series of national health and social care policies which have focussed explicitly on carers' rights to have their needs assessed, their health and wellbeing protected, access to support, training and employment, and to 'live a life outside caring' (Department of Health, 2010a; HM Government, 1999, 2008; Moran, Arksey, Glendinning, Jones et al., 2012). At the time of writing (March 2017) the latest iteration of a new National Carers Strategy was awaited from government. It is anticipated that this strategy will build on previous models and will focus *inter alia* on: raising awareness of the contribution of carers, and building more carer-friendly communities; recognising the diversity of carers and caring situations; and supporting carers in the most intensive circumstances, who are providing the greatest care and

who are at particular risk of crisis causing a breakdown in the caring situation. The findings of this review should inform implementation of the strategy and be of value in focusing attention on the evidence and knowledge base that should underpin policy and practice developments.

Table 1.1: The UK Carers Policy Timeline 1995 - 2016

Policy Development	Date	Main Provisions
Carers (Recognition & Services) Act	1995	The first ever UK legislation for carers, giving those providing 'regular and substantial care' the right to an assessment of their own needs.
Caring about Carers, first National Strategy	1999	To enhance the quality of life of all carers by means of improved information, support and care. Introduced a new Carers Grant for local authorities to support carers to have breaks.
Carers and Disabled Children Act	2000	Gave councils powers to provide services directly to carers; gave carers the right to an assessment independently of the person they care for; enabled local authorities to make Direct Payments to carers; increased councils' flexibility to offer short breaks.
Carers (Equal Opportunities) Act	2004	Introduced a duty on councils to inform carers of their rights to an assessment of their own needs; required councils to take account of carers' wishes to undertake employment, education, training and leisure activities.
Work and Families Act	2006	Extended the right to request flexible working to employees caring for adults.
'New Deal for Carers'	2006	Announced in the White Paper 'Our health, our care, our say' alongside a commitment to update and extend the PM's Strategy for Carers. Other parts of the 'New Deal' were a national information service for carers; a 'Caring with Confidence' training programme; and additional funding to local authorities for emergency home-based respite for carers in crisis.

Policy Development	Date	Main Provisions
Carers at the Heart of the 21st Century, updated National Strategy	2008	<p>Set out a vision that by 2018 “carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.”</p> <p>In particular five strategic outcomes:</p> <ul style="list-style-type: none"> • Carers will be respected as expert care partners, with access to services to support them. • Carers will be able to have a life of their own alongside caring; • Carers will be supported so they are not forced into financial hardship; • Carers will be supported to stay mentally and physically well and treated with dignity; • Children and young people will be protected from inappropriate caring and have the support they need.
Recognised, Valued, Supported (Next steps for the Carers Strategy)	2010	<p>Four priority areas identified:</p> <ul style="list-style-type: none"> • Identification and recognition; • Realising and releasing potential; • A life outside caring; • Supporting carers to stay healthy.
Care Act	2014	<p>The Care Act, 2014 consolidates much earlier legislation on care. It also gives carers new rights, and ‘parity of esteem’ with those they are caring for. From April 2015 carers have a right to an assessment if they appear to have needs (removing the need for care to be regular and substantial), and if they meet eligibility criteria they are entitled to support. Local authorities have new duties to promote wellbeing both for carers and those they care for. Clause 2 of the Act also places a duty on local authorities to prevent, reduce and delay needs for care and support. Clause 4 requires local authorities to establish an information and advice service on care and support (including for carers); there is also a duty to provide independent advocacy if</p>

Policy Development	Date	Main Provisions
		needed to support people in assessment and support planning.
Carers Strategy Call for Evidence Consultation	2016	Consultation launched in March 2016 (until 30 June) with a call for evidence to better understand the needs of carers and what can be done to support them to “enjoy a happy and healthy life alongside caring.”

- 1.19 The expectations and aspirations of carer-related policy and legislation need also to be seen in the wider context of social care reform and the introduction of the personalisation agenda, with themes of choice, control and empowerment frequently referenced (Larkin & Milne, 2013; Larkin & Mitchell, 2016; Needham, 2011, 2014). Nonetheless studies show many carers - such as the growing number of older carers - are still routinely overlooked and unsupported (Buckner & Yeandle, 2011; Glasby, Ham, Littlechild, & McKay, 2010; Pickard, King, & Knapp, 2016; Ridley, Hunter, & Rosengard, 2010). There is also evidence that carers’ willingness and ability to care is often assumed by social care workers conducting assessments of need, with the result that separate carers’ assessments are rarely offered (Department of Health, 2010b). Arksey and Glendinning have concluded that both the concept and practice of choice is “highly problematic” for carers (Arksey & Glendinning, 2007). An emphasis on choice, they suggest, ignores the complex dynamics of care-giving relationships and “conflates the needs and opinions of carers and the people they support into a single (implicitly harmonious) unit.” The tensions and contradictions between the interests of carers and those they support, and between the respective carers’ and disability political movements, remain unresolved.
- 1.20 This brief overview provides the background to our study; we turn now to outline the approach and methodology.

2 Approach and Methodology

- 2.1 A scoping review methodology was deliberately selected as the most appropriate for charting and synthesising a range of evidence and knowledge of considerable breadth and depth. In adopting a 'scoping review' model, we followed the approach developed by Arksey and O'Malley (Arksey & O'Malley, 2005), while recognising that scoping reviews are "a relatively new approach for which there is not yet a universal study definition or definitive procedure" (Pham, Rajic, Greig, Sargeant et al., 2014). Arksey and O'Malley helpfully distinguished between the general approach of a scoping review and a systematic review in the following terms:

"First a systematic review might typically focus on a well-defined question where appropriate study designs can be identified in advance, whilst a scoping study tends to address broader topics where many different study designs might be applicable. Second, the systematic review aims to provide answers to questions from a relatively narrow range of quality assessed studies, whilst a scoping study is less likely to seek to address very specific research questions nor, consequently, to assess the quality of included studies." (Arksey and O'Malley, 2005, P.20)

- 2.2 A scoping study not only adopts a different approach and methodology compared with a systematic review, but it has a different purpose and objectives. Pham et al again offer the following exposition:

"First, the purpose of a scoping review is to map the body of literature on a topic area, whereas the purpose of a systematic review is to sum up the best available research on a specific question. Subsequently, a scoping review seeks to present an overview of a potentially large and diverse body of literature pertaining to a broad topic, whereas a systematic review attempts to collate empirical evidence from a relatively smaller number of studies pertaining to a focused research question." (P.372)

- 2.3 Daudt et al have also contributed to applying and adapting Arksey and O'Malley's framework (Daudt, Van Mossel, & Scott, 2013), and proposed this definition:

"Scoping studies aim to map the literature on a particular topic or research area and provide an opportunity to identify key concepts; gaps in the research; and types and sources of evidence to inform practice, policymaking and research." (P.8)

- 2.4 Arksey and O'Malley's framework identified various reasons why a scoping study might be undertaken:

- To examine the extent, range and nature of research activity.
- To determine the value of undertaking a full systematic review (i.e. a preliminary mapping of the literature).
- To summarise and disseminate research findings.
- To identify research gaps in the existing literature.

2.5 They suggest that the first two purposes are part of an ongoing process of reviewing “the ultimate aim of which is to produce a full systematic review”, while the second two types “*suggest that the scoping study might be conceived as a method in its own right – leading to the publication and dissemination of research findings in a particular field of inquiry*” (P.22). Subsequent debate and discussion of these objectives by other researchers has confirmed the view that scoping studies are

“often misinterpreted to be a less rigorous systematic review, when in actual fact they are a different entity.” (Brien, Lorenzetti, Lewis, Kennedy, & Ghali, 2010) P.10

2.6 Our scoping study can be located within types 3 and 4: we are concerned with summarising and disseminating research (and knowledge), and identifying gaps in the existing evidence.

2.7 Arksey and O'Malley's framework had five main stages and a sixth they suggested was 'optional'. Subsequent commentary on the approach by other researchers has tended to conclude – as indeed did we - the consultation stage should be built in from the outset, although with room for interpretation about how it is achieved. The process between the stages they suggest is not linear but iterative, and may require reflexive repetition of different stages in order to cover the literature comprehensively. The stages are as follows:

- Identifying the research question.
- Identifying relevant studies.
- Study selection.
- Charting the data.
- Collating, summarising and reporting the results.

- Consultation exercise (optional)
- 2.8 There were a number of challenges in applying this framework to the present study. The ‘research question’ under consideration was one we had stated in extremely broad terms i.e. *“to comprehensively scope existing carer-related evidence and knowledge.”* This reflected our objective to draw together as much knowledge as possible from across the carer territory, but also to focus more broadly than looking only at research studies. This was a deliberate strategy, but it created significant challenges and logistical demands. Other recent scoping studies, although broad in approach, are quite specific in focus – looking at particular interventions or initiatives (Arksey & O'Malley, 2005; Brien et al., 2010; Daudt et al., 2013; Levac, Colquhoun, & O'Brien, 2010; Pham et al., 2014), Arksey and O'Malley, for example were addressing the effectiveness and cost-effectiveness of services to support carers of people with mental health problems. They identified 3,867 references, and 204 articles were selected for inclusion in the review.
- 2.9 The present scoping study, by contrast, was broad in both approach *and* focus; we were concerned not only with areas of practice or interventions, *but with the entire world of carers and their lives*. Our references and analysis were correspondingly wide
- 2.10 A scoping study is wide-ranging and seeks to map key concepts across a range of sources and types of evidence available. Indeed, the *breadth* of the approach is a distinguishing characteristic. The implications of this are significant. In the past, it has perhaps been assumed that a scoping study is a *rapid* alternative to a systematic review (Mays, Roberts, & Popay, 2001). Arksey and O'Malley challenged this perspective, and advanced the argument that a scoping review is both an entity in its own right, but not inherently quick or cheap.
- 2.11 All the scoping studies cited above used research teams with at least three full time equivalent researchers, and some employed large multi-disciplinary teams. Our study did not have such resources, being largely undertaken by one researcher. As such, we believe the resulting study offers a resource that is extremely useful, but which inevitably has some inherent limitations associated with the timeframe and resources available. An extended study would have allowed for an even wider ranging study and for greater depth of analysis. The logistical and practical demands of undertaking the study were considerable, particularly given the relatively limited resources and time available for the work. However, the resulting review has produced a resource that is wide-ranging, extremely rich in detail and that addresses multiple themes.

2.12 Inclusion criteria for the study were the following:

- Material published since 2000.
- Material available in the English language.
- Material focused on the care of adults.

2.13 The review searched for resources meeting the above inclusion criteria and where the title or abstract included 'carer' or 'caregiver'. Additional searches were undertaken using keywords which had been identified on *a priori* grounds including 'young carers'; 'older carers'; 'carers and health'; 'carers and employment'; and 'end of life care'. It was apparent that the generic search criteria were successfully identifying a wide range of references and citations and that these additional categories merely resulted in duplication. Searches were undertaken between June and December 2016. The following electronic bibliographic databases were searched:

- Academic Search Complete
- AMED
- ASSIA
- BNI
- CINAHL
- HMIC
- MEDLINE
- SCOPUS
- Social Care Online
- Web of Science

2.14 In addition, the resources from the JiscMail research email discussion list were searched, and miscellaneous other searches were undertaken in following reference lists. All materials were captured and saved using EndNote data management software, duplicates were removed and irrelevant materials screened out. In the following section, we map the range and type of material captured.

3 Mapping the territory

- 3.1 Sections 1 and 2 have presented the aims and objectives of the review and outlined the methodology that has been adopted in developing this scoping review. We turn now to address the findings of the review. We begin by summarising the major dimensions of the review findings, before examining themes and issues in greater detail.

An introduction to the data

- 3.2 After applying the inclusion criteria and removing duplicates, the review captured 3,434 references. The full reference list is presented in Appendix 1. The figures below indicate the distribution of material by source, and by type.
- 3.3 As Figure 3.1 demonstrates, three databases were especially productive (Social Care Online; HMIC; and Web of Science) and together accounted for more than 60 per cent of all references captured (respectively: 31%; 20% and 11%). Other data sources together contributed the remaining third of citations.
- 3.4 Materials were classified into 17 'types', but the top four categories together account for more than 90% of all classifications. Far and away the leading category (accounting for almost 70% of citations) was that of 'Journal Articles'. These were mainly peer reviewed articles in academic journals, but also included scholarly reflections and discussions of issues in other types of output. Other articles – particularly those identified in the professional and 'trade' press, which either report on events or developments, or which offer opinions on carer issues, were not included in this total and instead were coded as 'Magazine articles' (the second highest category at 313). 'Government Documents' represent the third highest category (271) and were gathered from across the GB Government as well as from the Northern Ireland Executive, the Scottish Executive, and the Welsh Assembly (and some from international resources).

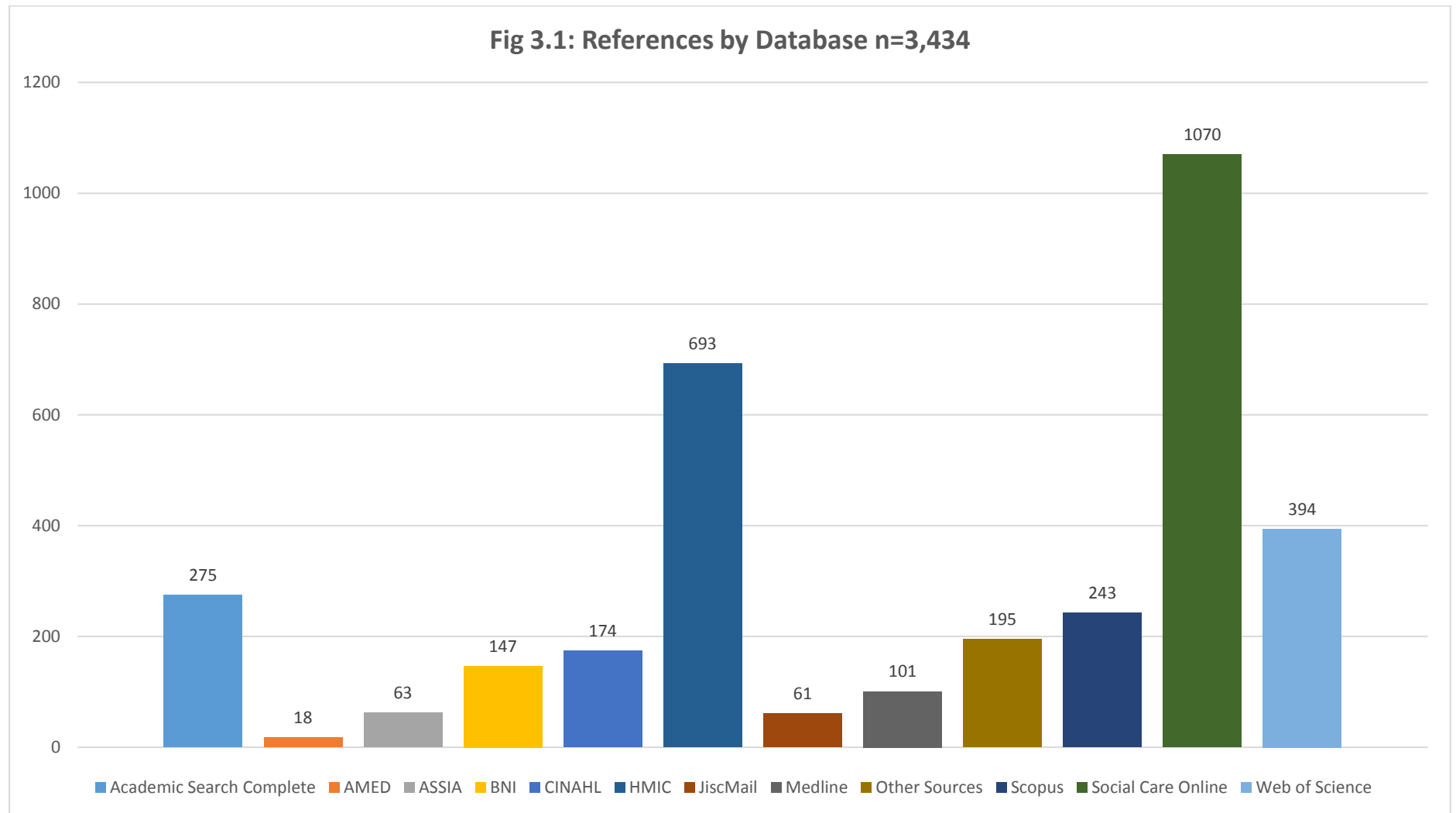
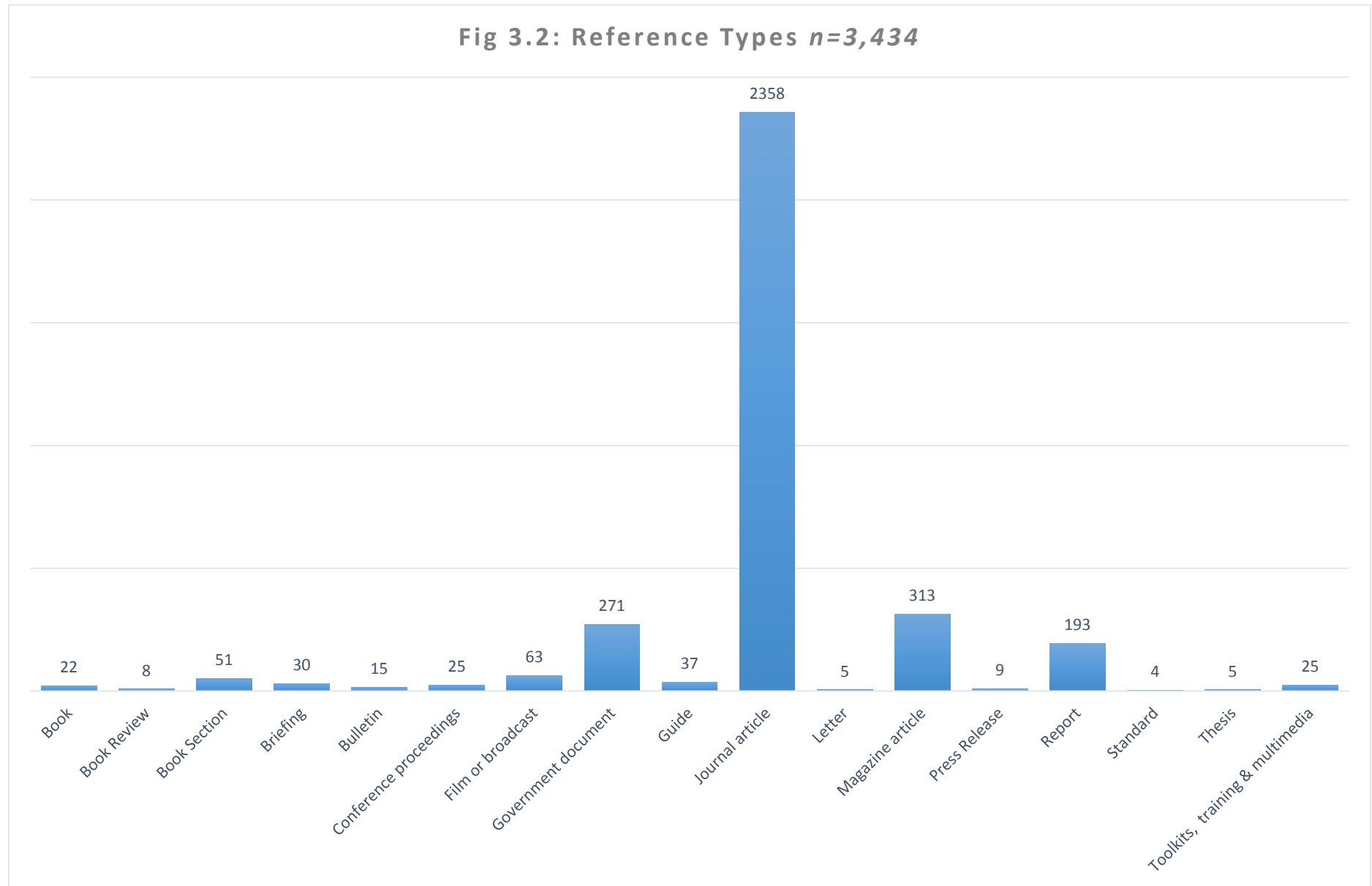


Fig 3.2: Reference Types $n=3,434$



- 3.5 Not all the government items are concerned exclusively – or even mainly – with carers, but they reference them as part of a wider focus on social care and related matters, and together these documents comprise an important part of the context to understanding the carer discourse. ‘Reports’ comprise the fourth highest category (193) and are a miscellaneous collection which includes academic reports of research published by universities and departments; by think tanks and policy research bodies (such as the King’s Fund; the Joseph Rowntree Foundation; SCIE etc.) and by government departments, Quangos and agencies). The category also includes a wider grey literature including reports issued by major bodies representing carers (including Carers UK; the Princess Royal Trust for Carers; Age UK; the Children’s Society etc.).
- 3.6 It is important to understand that the coding of reference types is not always absolute, and although each item has been assigned only one type, some have blurred edges and could fit more than one category. For example, it may be somewhat arbitrary to decide whether a resource is classified as a ‘Guide’ or as ‘Toolkits, training and multimedia’. To a considerable extent, the materials have been enabled to classify themselves, and resources that self-describe as a ‘guide’ or a ‘toolkit’ have been classed as such. Multimedia materials, toolkits and similar resources typically originate from third sector organisations, from specialist training companies, and from SCIE.
- 3.7 Increasingly, many of the resources and ‘documents’ exist only in electronic form rather than in traditional print. Moreover, there are also a range of digital materials emerging including computer programmes; toolkits and e-training; web-based resources; films and broadcasts. The range of material and of diverse types of resource also underlines the different audiences to whom they are directed. Thus, much of the academic literature might be seen as contributions to developing the theoretical discourse on carers, and promoting debate of policy and practice issues. Other categories, including reports, briefings, standards, toolkits and training materials are focused more on the improvement of services and support and delivering best practice. In classifying the material across the 17 types, no attempt has been made to establish a hierarchy or to imply that any given type is ‘better’ or ‘superior’ to any other. Rather, the point is to understand the complexity of knowledge about carers, and to underline the importance of different materials and resources existing and being accessible to a wide range of audiences with diverse needs and interests. Some of these will be carers themselves seeking information or advice about their own situation and needs.

Themes and Issues

3.8 The resources were coded and categorised into 62 themes. These were derived from keyword analysis of all references and identification of recurrent topics and issues. Dynamic 'Smart Groups' were then generated within EndNote to capture each cluster of references under all the headings. The themes, in turn, were classified within four major categories:

- **Carer Variables:** the characteristics and features of different types of carer and caring situations.
- **Type of Care:** the nature of needs of the cared for person, and the features of the care situation.
- **Impact of Care:** the consequences and sequela of caring.
- **Support and Carers:** The provision and impact of general and specific help and support.

3.9 There is some blurring of the edges and the categories are not absolute. For example, some of the themes under 'impact of care' will also blend into 'support', but in general the four categories discriminate well and cumulatively describe the full landscape of the knowledge and literature. Figure 3.3 presents a visual representation of the distribution of themes between categories, while Table 3a presents a glossary defining the categories and each of the themes.

Figure 3.3: Themes classified by Category $n=62$

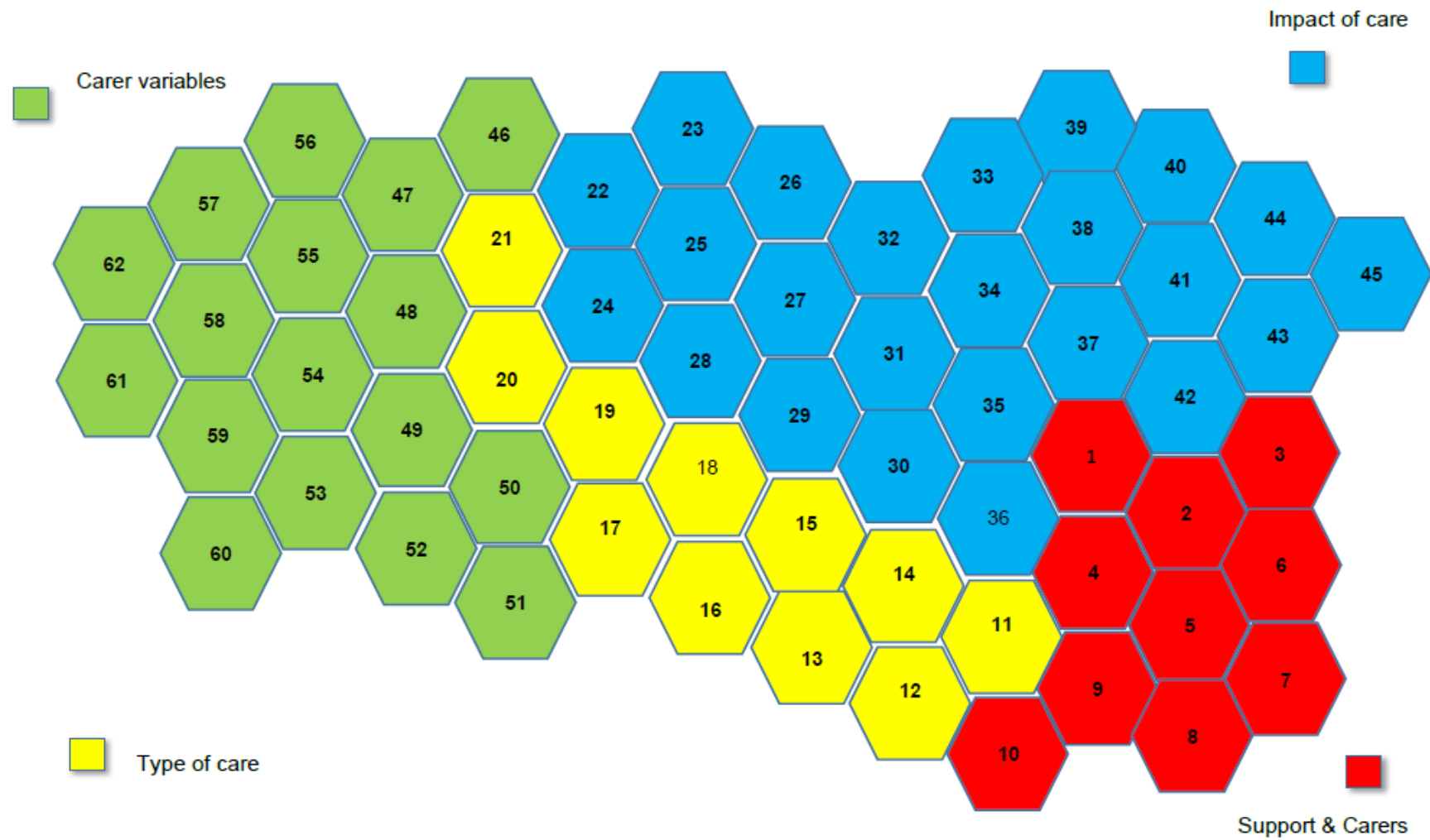


Table 3a: Glossary of Terms – Categories and definitions of themes

Support & carers	
1. Assessment	Assessment of carers' needs.
2. Care Act evaluation	Focusing on the implementation of the 2014 Care Act and considering the impact on and implications for carers.
3. Carer Support	Addressing carers' needs for support, or specific services/interventions intended to support carers.
4. Cash for care	Refers to Direct Payments, personal budgets and similar arrangements that provide cash to the carer to organise support on their own behalf and/or that of the person cared for.
5. Respite	Services and interventions intended to provide respite or a break for the carer and/or the person cared for.
6. Social support & networks	The nature of family, friends and wider community networks able to support carers.
7. Social Work Education	The involvement of carers in shaping social work education and training, and the importance of carers issues being reflected in course content.
8. Technology & telecare	Use of telecare, technology, telematics, robotics, electronic tracking etc. and applications for carers and those they support.
9. Training & carers	Training for carers, and involvement of carers in training of care providers and others.
10. Value of care	The notional value of care provided by carers, and the value attributed to caring (monetary and other).
Type of Care	
11. AIDS/HIV	Caring associated with the needs of people with AIDS/HIV.
12. Cancer	Caring for people who have cancer.
13. Caring for older people	Caring for older people, and the needs associated with ageing.
14. Complex needs	Caring for people who have multiple and/or complex care needs.
15. Dementia	Caring for people with dementia.

16. End of life	The particular caring needs and issues associated with end of life and palliative care.
17. Learning disability	Caring for people with a learning disability, and carers who have a learning disability.
18. Long term conditions	The particular care needs and issues for carers of people with chronic long term conditions.
19. Mental health	Caring for people with mental health needs, and the mental health needs of carers.
20. Nature of care	What caring involves – what care is provided.
21. Stroke survivors	Caring for people who have had a stroke.
Impact of Care	
22. Abuse & care	Caring relationships can sometimes be abusive, for the cared for and/or the carer.
23. Bereavement	The impact of bereavement on carers.
24. Burden of care	The experience of caring as a burden.
25. Care costs	The costs of caring and the economic impact of care.
26. Carer depression	Depression in carers as a result of caring.
27. Carers and health	The impact of caring on carers' health and wellbeing.
28. Carers and employment	The impact of caring on carers' labour force participation, and implications for employers.
29. Carers needs	Carers' needs for support in caring.
30. Conflict in caring	Boundaries, tensions and trade-offs in caring relationships.
31. Crisis	Crisis in the supply of care, and in carers' capacity to continue caring.
32. Emotional and physical impact	The impact of caring on individual carers.
33. Entering residential care	The decision to place a person in residential care and the impact on carers as they continue to care in a new context.
34. Ethical issues in caring	Ethical issues and dilemmas that arise in care.
35. Lifecycle and care	The transitions to care over the life course.

36. Measuring and evaluation	Outcomes and measuring impact of care.
37. Post-caring	What happens to carers when the caring situation ends.
38. Psychological impact	Psychological impact of caring; and psychological interventions aimed at improving well-being.
39. Quality of life	The quality of life of carers and those they care for – the positive and negative effects of caring.
40. Resilience & coping	Carers' resilience, and the strategies they adopt in coping.
41. Risks in care	Practical and psychological risks in caring situations for both carers and those they care for.
42. Satisfaction & caring	The satisfactions people derive from caring, or satisfaction with particular support.
43. Social exclusion	The impact of caring on social inclusion and participation.
44. Stress & strain	The emotional costs of caring and the experience of related stress.
45. Longitudinal study	Longitudinal investigation of carers and caring situations.
Carer Variables	
46. Adult children	Adults caring for parents/in-laws, and parents caring for adult children with disabilities.
47. Carer characteristics	The characteristics and features of carers in different situations and relationships.
48. Caring at a distance	Long distance care, and managing care when not co-resident or in propinquity.
49. Cultural factors	Cultural and social factors that affect caring situations and relationships.
50. Ethnicity	Specific aspects of caring in BME communities.
51. Expert carers	Carers as experts in the needs of those they care for.
52. Friends, neighbours & siblings	Carers supporting friends, neighbours or siblings.
53. Gender & care	Gender differences and similarities in carers.
54. Hidden carers	The challenges of identifying and finding carers who are hidden or hard to reach.
55. LGBT	The caring situations of LGBT carers and those they support.

56. Older carers	Ageing carers and their needs.
57. Projections of carer supply	The future of care; predicting supply and demand factors.
58. Relationships & care	The multiple relationships in caring including parents; children; siblings; intergenerational care; mutual support; non-kin care, and other caring dyads.
59. Sandwich carers	The specific situation of carers with simultaneous responsibilities for parents and children, and for managing care alongside other demands.
60. Rural issues	Particular issues and challenges for carers in rural areas.
61. Spouse care	Caring for a spouse/partner and co-dependency.
62. Young carers	Young people – children and young adults – who are caring for other family members and are often hidden from view; their needs and support.

3.10 The 'honeycomb' diagram demonstrates the number of themes distributed across the four categories, so:

- 27 per cent address **carer variables**;
- 18 per cent are concerned with the **type of care**;
- 39 per cent explore the **impact of caring**;
- And 16 per cent of themes are to do with **support and carers**.

3.11 However, Figure 3.4 presents a slightly different picture by looking at how the themes are distributed across the categories. References can appear under multiple themes; so, the overall total of attributions (that is, the 13,373 'Smart Group' allocations) is far greater than the number of discrete references (3,434) because each source is counted every time it appears under one of the 62 themes. While the 'Impact of Care' remains the leading category accounting for around 50% of attributions, 'Carer Variables' which account for 27% of identified themes, actually represent just 12% of all reference attributions, while Support & Carers, and Type of Care which respectively accounted for 16 and 18 per cent of themes, both account for just under 20 per cent of all attributions. Figure 3.5 outlines the complete distribution of themes by frequency.

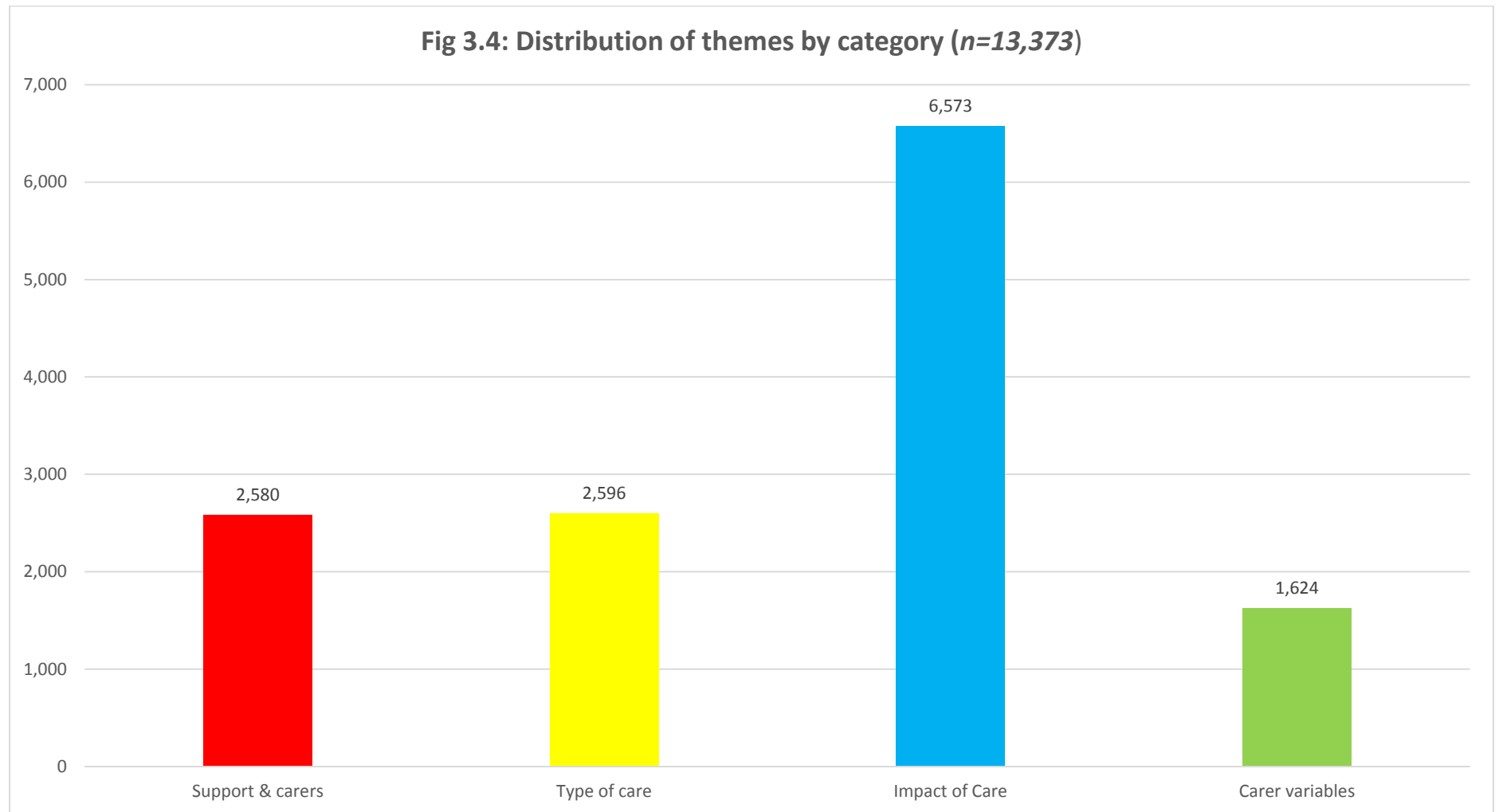
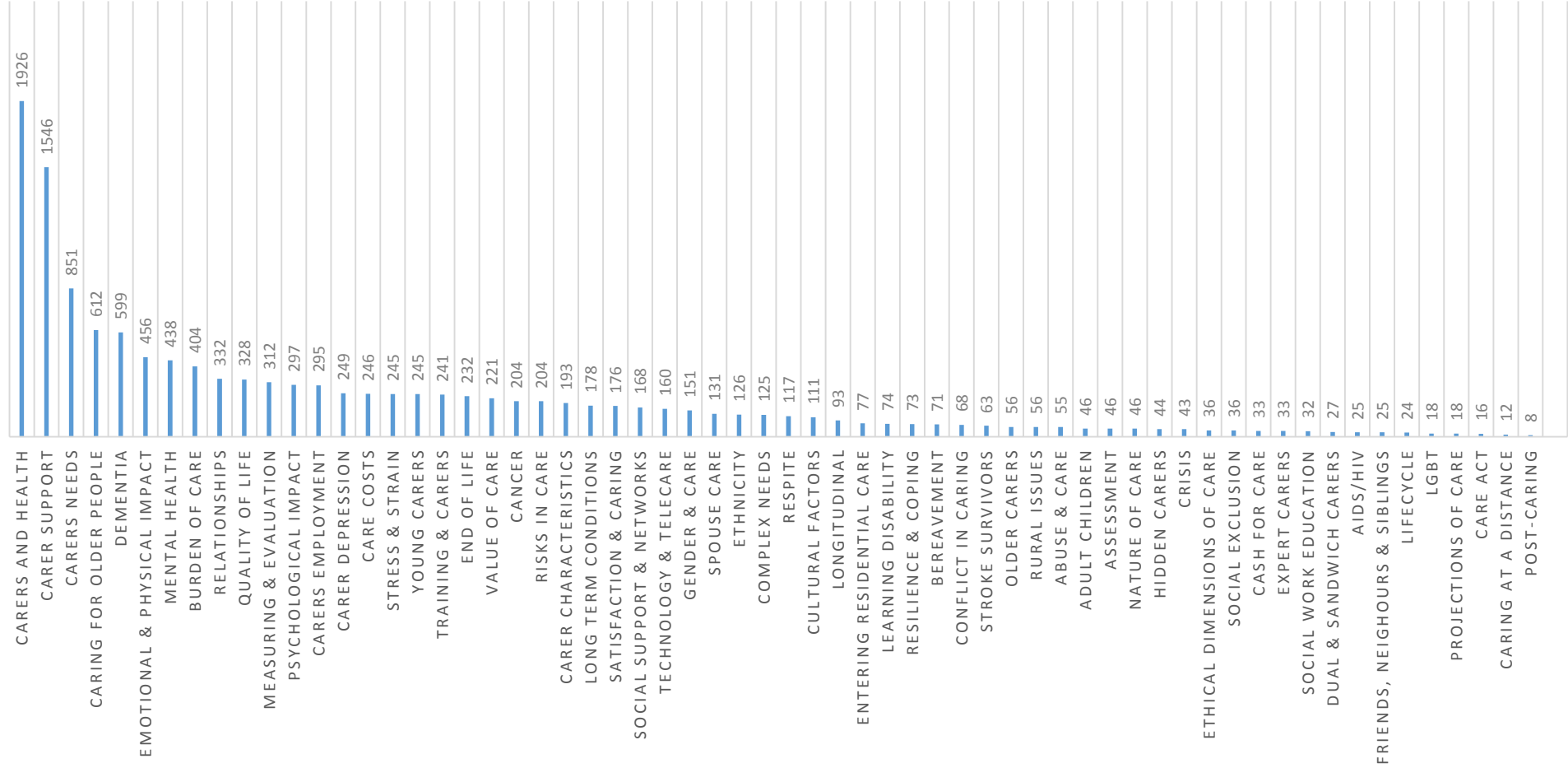


Fig 3.5: Thematic Frequency N=13,373



- 3.12 The pattern of distribution is strikingly varied. By far the largest number of thematic references are to 'Carers and Health', which includes the sub-themes of 'Health impact'; 'Carers'/caregivers' health' and 'Health consequences'. Some of these references will reflect the health of people being cared for, but a very large number are concerned with carers' own health and well-being. Of the dozen most frequently identified themes, 7 (58%) are concerned with aspects of the impact of caregiving; half of the least frequently identified themes addressed variables in the carer population. The 12 most and least frequently identified themes are summarised below:

Table 3b: Most and least frequently identified themes

Top 12 themes	No.	Bottom 12 themes	No.
Carers & Health	1,926	Cash for care	33
Carer support	1,546	Expert carers	33
Carers' needs	851	Social work education & carers	32
Caring for older people	612	Dual & sandwich carers	27
Dementia care	599	AIDS/HIV & carers	25
Emotional and Physical impact	456	Friends, neighbours and sibling carers	25
Mental health	438	Caring & the lifecycle	24
Burden of care	404	Projections & care demography	18
Relationships	332	LGBT & carers	18
Quality of life	328	The Care Act & Carers	16
Measuring & evaluation	312	Caring at a distance	12
Psychological impact	297	Post-caring	8

- 3.13 This charting of frequencies is intrinsically interesting and begins to enable us to map out the terrain of research and knowledge on carers. Documenting the peaks and troughs reveals the areas that have attracted considerable focus and those that are relatively under-explored; it is also a reflection of research funding, and policy, priorities to-date. This is not necessarily an argument for giving equal attention to all aspects of caring, but it *does* allow us to better understand where the gaps and deficits in knowledge are likely to be found; where there appears to be considerable evidence

and knowledge, and where future analysis, exploration, policy prioritising and research commissioning might most fruitfully be directed.

- 3.14 We turn now to examine the nature of knowledge in greater depth, and we do so by using the four-fold categorisation to cluster the themes.

4 Scoping the Knowledge: a) Carer Variables

- 4.1 As we have described earlier, this is *not* a systematic review, and following Arksey and O'Malley (Arksey & O'Malley, 2005), our prime concern has been to map the body of literature and knowledge on the topic of carers, rather than – as a systematic review would do – summing up the best available research on a specific question. Nonetheless, peeling back the layers and examining the knowledge in more detail allows us to explore the territory in more granular detail. It is not possible to individually review and analyse all 62 themes that are identified; however, by looking through the lens of the four categories some of the major themes, issues and questions can be highlighted. Sections four to seven of the report provide the analysis and narrative for each of the categories in turn.
- 4.2 The themes that are clustered under the heading of 'Carer variables' all relate to characteristics and features of carers themselves. The largest number of references occur under the sub-heading of 'Relationships and care' (332), and are indicative of the complexity and multi-dimensional nature of care and caregiving. However, all the references under this heading also appear under other classifications that provide a more specific or detailed analysis.

Relationships and Care

- 4.3 All care takes place within a relationship, and typically that is a dyadic relationship, whether between parent and child; between spouses or partners; between siblings, or between friends or other non-kin carers. Caring both reflects the nature of a given relationship, but can also impact on and change the nature and quality of that relationship. Being a carer can overshadow and fundamentally alter previous relationship identities; while the nature of pre-existing relationships can have a positive or negative influence on willingness to provide care (Lyonette & Yardley, 2003).
- 4.4 Almost all the items captured within this sub-heading (95%) are Journal Articles and reflect academic investigation of caring relationships, and qualitative study of people's experiences. For example, Asabø et al examine how the spouses of people with COPD accommodate and integrate their role as carers with that of spouses, and the tensions and conflicts this creates (Aasbø, Solbraekke, Kristvik, & Werner, 2016) The authors propose the use of the concept of 'biographical we' as a way people strive to maintain a sense of continuity in their lives. Identifying as a carer can create

ambivalence and discomfort; the literature reveals that people can find a carer identity difficult to assume or to distinguish from the normal expectations and roles of family and partner relations (Corden & Hirst, 2011). Caring for a spouse or partner is predominantly – but not exclusively – the experience of older people, and:

“As couples age, both partners are more likely to need and give support, and the boundaries between providing and receiving care can be blurred.” (Corden and Hirst, 2011, P.219)

- 4.5 Non-identification, or late self-identification as a carer can be significant particularly when it impacts on access to services and support, or to benefits such as Disability Living Allowance and Carers Allowance. Corden and Hirst point to the need for further research to better understand the circumstances associated with adoption of a carer identity, and the implications the identify has both for the person’s experience of care giving, but also in their use or take-up of services (Corden and Hirst, 2011, P.237).
- 4.6 The focus on relationships has been explored through various lenses, but particularly around caring for people with dementia, and care giving for stroke survivors. In both situations there are often personality and behavioural changes, and the impact on family dynamics is particularly challenging (Ablitt, Jones, & Muers, 2009). The meaning of caring has also been conceptualised around ‘caring as worrying’; exploring the complex emotional relationship of responsibility among spouse carers supporting a partner with MS for example (Cheung & Hocking, 2004).
- 4.7 The impact of caring on relationships is likely to be similar in many contexts, but there are distinctive aspects in respect of young carers (i.e. children and young people who assume premature responsibilities in caring for other family members, usually a parent). These issues will be considered more fully below, however, the negative impact on psychosocial development of young people is a matter of particular concern (Collins & Bayless, 2013).
- 4.8 Evidence on the impact of caring on relationships is also a finding of survey work undertaken by the Carers Week Partnership which reported that more than 7 in 10 (71 per cent) of respondents were not prepared for the change in relationship they experienced with the person they cared for. Nearly six out of ten respondents had experienced difficulties in their relationship with the person they cared for, although some (two out of five) reported *an improvement in their relationship* (such as by becoming closer). The survey findings also point to the impact on wider relationships,

with breakdown in other family relationships and fractured friendships (Carers Week Partnership, 2013)

- 4.9 How people become carers is often complex, and we will examine issues around self-identification elsewhere. But, who cares within families, and why one person rather than other family members become involved speaks to the complexity of relationships and the range of dyads involved. Sebern and Whitlatch point out that while family care intrinsically involves (at least) two people, the majority of research and intervention studies on family care focus on only one person from the care dyad, but in a dyadic process “each participant affects and is affected by the other” (Sebern. & Whitlatch, 2007)
- 4.10 Other analyses focus on ‘networks’ rather than dyads to conceptualise and understand caring relationships. Keating et al, for example, distinguish between ‘social’, ‘support’ and ‘care-giving’ networks, and consider the extent to which social networks “evolve into care-giving networks when a member has an increased care need” (Keating, Otfinowski, Wenger, Fast, & Derksen, 2003). Nocon and Pearson similarly focus on the role of friends and neighbours in supporting older people, recognising that such support “generally appears to be different in quantity and kind from that provided by family carers”, although there is a ‘fuzzy boundary’ between neighbourliness, friendship and care (Nocon & Pearson, 2000).
- 4.11 Charlesworth et al explored the relationship between caring and social networks among carers of people with dementia. Carers are likely to experience reduced social networks because of fewer opportunities to socialise and because of the stigma of caring; carers are generally likely to report less social interaction and fewer friendships than non-carers (Charlesworth, Tzimoula, Higgs, & Poland, 2007).
- 4.12 Analysis indicated that carers with private restricted networks (i.e. with the least regular contact with family, friends or neighbours) were most likely to make use of a befriending intervention., and this group was seen as precisely the one “for whom gaining such a relationship would have made a notable difference in their social network type and level of social isolation” (Charlesworth et al., 2008, P.42). The authors suggest that one practice implication of the findings would be to take account of network types when undertaking carer assessments:

“These could take account of whether informal networks were likely to continue to provide appropriate levels of types of support and whether home-based service support could complement network functions.” (P.42)

- 4.13 Lapierre and Keating’s secondary analysis of the 1996 General Social Survey of Canada distinguished between friend and neighbour carers who differed both in terms of their characteristics and in the nature of support provided (Lapierre & Keating, 2013). However, such analysis has limitations as the authors acknowledge, reflecting the variables and definitions used in the original study and not providing – for example – information about the people being supported by this non-kin care. The data also provide limited insight to the nature of the caring relationship:

“In this study we were able to describe only those neighbours and friends who became involved in care-giving, leaving remaining gaps in our understanding of how friends and neighbours contribute to the informal care sector. We do not know anything about the history of these relationships prior to the provision of care, or how these individuals emerged as carers. Future research needs to place non-kin carers within the context of the social and care networks of care recipients to determine the extent to which contributions of friends and neighbours are contingent on network composition.” (Lapierre and Keating, 2013, P.1464)

- 4.14 Rutherford and Bowes’s analysis of British Household Panel Survey data together with qualitative interviews of older people and carers mapped ‘networks of informal care’ to better understand and describe the complexity and nuanced nature of caring (Rutherford & Bowes, 2014).

- 4.15 Despite the complexity of relationships, and the changes which occur over a lifetime, there are significant gaps in knowledge and understanding of these dynamics. Blieszner, for example, points out that gerontological research is ‘unbalanced’:

“Most of that work addresses caregiving by spouses and adult children, but studies of caregiving by siblings, extended kin, and friends are less prevalent. Less is known about how needed care is provided to ever-single persons and those who are estranged from relatives than to those experiencing more normative family settings as they age.” (Blieszner, 2006)

- 4.16 Similarly, there has been relatively little attention paid to following relationships over extended periods of time, which again is particularly relevant to older people and a lifetime of relationships.

- 4.17 Care by siblings can be associated with young carers, but another dimension concerns adult sibling carers of people with learning disabilities for whom the transition to the role of primary carer typically occurs late in the lifecycle. Coyle et al examined this transition through qualitative research with adult sibling carers of people with intellectual and development disabilities (I/DD) in the USA and identified “a unique set of challenges for sibling carers of adults with I/DD associated with the transition of care from the parent to the sibling carer” (Coyle, Kramer, & Mutchler, 2014). The ageing process was seen to permeate the care providing role, both in terms of the ageing of the person with learning disabilities but also of the sibling carer and other family members:

“They key finding of our study is that aging of the family system as a whole (parents, care recipient with I/DD, sibling carer, and other non-care providing siblings) shapes the transition in unique ways.” (Coyle et al, 2014, P.309).

- 4.18 The similarities between the experiences of these sibling carers and those of older carers who are adult children or spouses include stress reported by participants, life choices triggered or necessitated by the caring role (including retirement from paid employment), and “Intrafamily struggles and negotiations that were required in establishing and maintaining supports within the family system” (P.310). The experience of caring for adults ageing *with* disability was recognised to be both similar to, and different from that of caring for people ageing *into* disability.

- 4.19 Taggart et al point out that the needs of ageing family carers and of older people with intellectual disabilities reflect the greater life expectancy for people with learning disabilities, and mean that they are now more likely to live with a family member who will also have additional support needs (Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). The illness or death of a parent is often the trigger for unplanned challenges and dilemmas for siblings and other relatives suddenly confronting ongoing care for their family member. Their qualitative research in Northern Ireland with 112 parent and sibling carers revealed the lack of planning typically given to questions about future care despite carers experiencing ‘unremitting apprehension’:

“Contemplating future planning was emotive and disturbing, with many carers reporting not wanting to explore this complex topic. Despite constant worry about what would happen to their relative when they could no longer care, many carers in this study had failed to develop a plan for the future care of their relative.” (Taggart et al, 2012, P.228)

- 4.20 Some carers *had* apparently made plans whereby siblings would take over care responsibilities, but these generally appeared fragile, or indeed merely ‘aspirational’:

“These parents had not directly discussed the future care options of their son/daughter with intellectual disability with other family members. The carers were therefore hoping or expecting that these non-disabled siblings would take on this caring role when they died.” (P.227)

- 4.21 As has been noted previously, much of the focus of research on care has been on the relational aspects of care-giver and cared for, but this dyad is often nested within wider family and social networks of caring relationships. The negotiation of caring responsibilities and decisions particularly between siblings concerning who takes on major caring responsibilities, or how these are shared, is one aspect of this wider context. Leinonen’s research with Finnish adult child carers (Leinonen, 2011) identified three main patterns of responsibility between siblings: absence; backup; and togetherness. While various rationales were offered to account for differential sibling responsibilities (such as different child care and employment commitments), interviewees recognised the mediating role of relationships:

“They stress the relational nature of human life course: the lives of the family carers were linked with the lives of other actors involved in a care relationship. The interviewees stressed that either the relationship between adult children and parent(s) or the relationships among the siblings influenced the division of care duties.” (P.324)

- 4.22 Turning from the wide category of ‘relationships and care’ to the finer detail of knowledge about the nature of carers, the major dimensions that are distinguished are: young carers; spouse carers; older carers; adult children; gender and ethnicity.

Young Carers

- 4.23 Young carers are officially defined as children aged under 18 who help to look after a relative with a condition, disability, illness, mental health condition or a drug or alcohol problem. The 2011 census found 177,918 children aged 5-17 in England and Wales had caring responsibilities (2.1% of the cohort), typically young carers are helping care for a parent or sibling. Some estimates put the figures much higher, and the Carers Trust, for example, cites the figure of ‘about 700,000 young carers in the UK’. Despite young carers representing a small proportion of the total carer population (five million

people aged 16 and over in England, and 12 per cent of adults), it is clear that research interest and campaigning efforts are being increasingly directed towards young carers, as reflected in the analysis presented here in which the theme of young carers was the second most prevalent within the category of carer variables.

- 4.24 The ‘discovery’ of young carers in research and related literature, both in the UK and internationally (Becker, 2007), is reflected in the work that has been undertaken in estimating prevalence, but also in more in-depth and qualitative exploration of the experiences of young carers and the impact of caring on their lives, particularly on their education. The Young Carers Research Group (YCRG) was founded at Loughborough University in 1992 and is associated with a lot of the initial identification of the phenomenon of young carers. Similarly, the members of the National Young Carers Coalition (notably The Children’s Society and Carers Trust) – established in 2008 – feature prominently in campaigning and in highlighting the situation of young carers.
- 4.25 Critical analysis has highlighted the need to challenge representations of young carers as ‘victims’ or ‘heroes’ and to understand the impact of caring on their lives and the implications for their own wellbeing (Aldridge, 2008). There has been particular focus on the situation of children and young people caring for parents with mental health problems, and the worry young carers often experience about the consequences – both for themselves and for the family member they care for - of asking for help (Aldridge, 2002, 2006). The failure of many services to address the needs of both the cared for person and the young carer has been identified, as has the assumption that children are automatically at risk where there is severe parental mental illness.
- 4.26 The consequences of caring for young people can include psychological and physical stress; social isolation, and educational under achievement (Charles, 2011) (Hounsell, 2013). Nonetheless, research has also found positive outcomes associated with caregiving, including self-worth, satisfaction in care-giving and a sense of maturity (Charles, 2011). Bolas et al have similarly identified the multidimensional experience of young people as carers including:
- “Searching for meaning; feeling isolated from others and actively withdrawing from their social worlds; and attempting to integrate caring into their self-concepts and everyday lives.”* (Bolas, van Wersch, & Flynn, 2007) P.845
- 4.27 The experiences of young carers are in many ways similar to those of carers of any age, but Bolas et al emphasise the complexity of impact particularly as it typically

occurs at a time of major change and challenge associated with adolescence. The negative impact on young carers' educational attendance and achievement also has enduring consequences for their subsequent employment prospects, with young adult carers being less likely to be in education, training or employment (Hounsell, 2013).

4.28 Much of the focus on young carers has been on those caring for sick or disabled parents, and the 'parentified child' is a recurrent theme to describe and analyse the role reversal that can occur with children assuming adult responsibilities (Earley & Cushway, 2002).

4.29 The dominant paradigm of young carers research has been criticised on several fronts for the assumptions it makes about the nature of disability and the implied inadequacy of disabled parents. Banks et al, for example, review the shortcomings of various models and suggest that alternative conceptual frameworks are required that allow consideration of children and young people in a more complex and inclusive way and within the context of their family (Banks, Cogan, Deeley, Hill et al., 2001). One of the particular challenges to the conceptualisation of 'young carers' concerns the conclusion in much analysis that children with caring responsibilities need support in managing these, whereas Banks et al point out:

"Critics question the criteria for being classified as a young carer. At the same time, they maintain that far from supporting young carers in taking on responsibility for another family member, the emphasis should be on pressurising local authorities to support families adequately so that the role of the young carer becomes redundant." (Banks, 2001, P.810)

4.30 While supporting young carers is vital, it is recognised in much of the discourse that there are risks that support effectively institutionalises responsibilities and serves as "propping up exploitative caring arrangements" (Banks, 2001, P.812). Adequate support to the sick or disabled person is essential to relieve caring demands, and particularly personal care that both children and their families view as inappropriate (Dearden & Becker, 2004). Getting the right balance in supporting young carers and those they care for is often emphasised within a 'whole family approach', but this recognises that there are inherent tensions and contradictions between different interests, and within the context of a wider social, economic and political context (Frank, 2002).

Adult Children as Carers

- 4.31 Care by adult children, particularly those born in the 'baby boomer' generation (1945-54) is the model that has traditionally been most closely associated with the concept of the carer. Ogg and Renaut point out that compared to their parents at the same stage of the life course, people born between 1945-54 were more likely to have at least one parent still alive, and were also likely to have living siblings (Ogg & Renaut, 2006). Their analysis of data from the Survey of Health, Ageing and Retirement in Europe (SHARE) confirmed the continuing importance of support from adult children in both Northern and Southern European countries, although in the latter there was closer proximity of generations (more shared households) and a greater likelihood of providing daily care or support.
- 4.32 Most informal care for older people in England is provided either by an adult child, a spouse, or both. Care by an adult child is particularly important for people aged over 85, where the likelihood of having a surviving spouse is considerably reduced (Pickard, 2008). The future availability of care by adult children is expected to decline for a number of reasons including smaller families; increased childlessness among future cohorts of older people; the decline of co-residence of adult children and their parents, and the continued increase in women's employment. The supply of spouse care – as explored below – is expected to continue to increase as improved male mortality reduces the number of widowed women (Pickard, 2008).
- 4.33 Pickard's analysis and projections of supply of intensive care to disabled older people by their adult children in England indicates a growing 'care gap' between the demand for care and its supply with effect from 2017. The vast majority (around 90 per cent) of those providing intense care to parents (i.e. of more than 20 hours per week) are themselves aged under 65, and increasing the provision of care will intensify demands on these working age carers.
- 4.34 Bastawrous et al explore the unique aspects of care by adult children in terms of the role reversal aspects of relationships, and consider how changes in the parent-child dynamic can impact negatively on health and wellbeing (Bastawrous, Gignac, & Kapral, 2015). Their scoping review identified the features of the demands on adult child carers (ACCs), and specifically the number of different demands arising from a range of relationships and potentially giving rise to role conflict in ways that was not the case for spousal carers:

“While the findings suggest that wellbeing is not impacted by the number of roles an ACC occupies, the combination and quality of these roles can result in limitations on time that lead to role conflicts.” (Bastawrous et al, 2015, P.463)

- 4.35 The other factor mediating ACC wellbeing was identified as the quality of the parent-child relationship. However, it is unclear from the literature how relationships change and influence wellbeing over time, and the authors point to the importance of a longitudinal focus in future work to inform understanding “of the changes that take place in the parent child relationship and multiple role involvement across the care-giving trajectory” (P.449).

- 4.36 Gans et al have explored the ‘trade-off’ between caring for children and caring for parents; they argue that in previous generations adult children were relatively free of childcare responsibilities by the time they needed to care for older family members (Gans, Lowenstein, Katz, & Zissimopoulos, 2013).

“However, current demographic trends reflect the changed timing of the two formerly independent periods of care – childcare and parental care – creating a potential overlap.” (P.456)

- 4.37 Not only is this a reflection of delayed childbearing but also of the lengthening of adolescence, with young adults delaying their independence for economic and other reasons, and meaning that middle aged parents may continue to support their ‘boomerang children’ for extended periods. This concept of the ‘sandwich generation’ of women with caring responsibilities for children and parents was coined in the 1980s although studies of the time found a low likelihood for women to be in this position. More recent research suggests that in Britain one third of women aged 55-69 are providing care to both younger and older generations (Grundy & Henretta, 2006). On the basis of current demographic trends Gans et al conclude that this simultaneous provision of support to more than one generation will become more prevalent.

- 4.38 Grundy and Henretta point out that having dependent young children while also caring for parents is rare, and requires both delayed child bearing and early onset of illness or disability in parents. Nonetheless:

“Much more common are families in which the potential call for simultaneous support comes from adult but still partly dependent children and from elderly parents. Adults, particularly women, in late middle age are the most likely to face these two-way commitments.” (Grundy & Henretta, 2006, P.709)

- 4.39 Exchanges of help among three generations, they argue “will become increasingly important as these family arrangements become more common”. Grundy and Henretta identify the need for more research around these complex issues, particularly recognising the limitations of cross-sectional data. Further exploration is also required to better understand the trade-offs in helping one or other generation.

“..an important constraint on help that involves giving money or spending time is that it involves scarce resources, trade-offs and opportunity costs. Unlike affection or emotional closeness, spending money or time on one generation implies that someone or some others – the other generation, the donor, or their spouse or partner – receives or retains less.” (Grundy & Henretta, 2006, P.720)

- 4.40 Evandrou and Glaser’s analysis of major data sets (British Household Panel Study; Family and Working Lives Survey; General Household Surveys, and the longitudinal Retirement Survey) also analysed the generation caught in the middle between simultaneous work and family roles, but concluded this pattern “remains atypical in Britain” (Evandrou & Glaser, 2004).

“However, a higher proportion of mid-life individuals hold multiple roles at some point in their life course than at a single point in time. In addition, comparison across birth cohorts shows that multiple role occupancy is increasing, and it is likely that the proportion of men and women who juggle work and family responsibilities will continue to rise.” (Evandrou & Glaser, 2004, P.787)

- 4.41 The extended period of responsibility for adult children, particularly those that return to share the parental home for extended periods, is lengthening the period of parental responsibility “into and beyond mid-life”. The impact of this on quality of life (financial and physical/mental wellbeing) requires further attention.

- 4.42 Some of the implications of combining different role responsibilities are also addressed elsewhere in this report when considering the impact of care, but it is clear that juggling the demands of caring for children and other relatives with paid employment is a key dimension of this ‘sandwich care’. Work undertaken by Carers UK and Employers for Carers has also illuminated these challenges and emphasised that “one in seven people in the workplace are likely to have caring responsibilities and that many of these employees may be juggling multiple caring roles” (Carers UK/Employers for Carers, 2014).

Older carers, Spouse and Partner care

4.43 As might be expected, there is considerable overlap between knowledge and research on spouse (and partner) care and that on older carers. Moreover, with the continued ageing of the population, the role of the older spouse carer is expected to be increasingly important (Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000). Older carers differ from other carers in some important respects; analysis of data has found strong correlations between type of relationship and type of household, which in turn has an impact on the nature of care. Thus, co-resident carers are typically spouses or cohabitants, and are more heavily involved in care than non-resident carers (Milne & Hatzidimitriadou, 2003b).

4.44 Older carers have tended to be relatively invisible in both research and policy, but the importance of supporting them should be compelling:

“Older carers can be distinguished from other groups of carers in a number of unique ways: they are more likely to live with the person they care for, care-giving is likely to take place within the context of a long-term relationship and there is a greater chance of carers having health problems of their own. Dementia is also more likely to be a feature of caring in later life.”

And

“There is clearly a high level of devotion to caring amongst many co-resident older carers; they often provide intensive care over a long period of time in very demanding circumstances with little or no support from services.” (Milne and Hatzidimitriadou, 2003, P.12).

4.45 Older carers and spouse carers are particularly likely to need to cope with the demands not just of their partner’s physical infirmity, but also of cognitive decline, behavioural change and communication difficulties that are associated with dementia and with the incidence of strokes. In the case of the latter, the transition to the role of carer can be sudden and dramatic with no prior warning, and carers in such situations often experience significant strain and psychiatric morbidity (Draper & Brocklehurst, 2007). Social isolation can be a particular consequence for both carers and stroke survivors because of the physical and psychological impact of the condition (Quinn, Murray, & Malone, 2014) (Cheater, 2008). Spousal care is distinguished, Milne and Hatzidimitriadou observe, by

“its mutuality and interdependence with the carer/cared for roles being indistinguishable from one another. Caring within marriage, unlike most other caring relationships, tends to be regarded by carer and cared for as an extension of the intimacy and companionship that characterises marriage.” (Milne and Hatzidimitriadou, 2003, P.7)

- 4.46 This underlines both the difficulties that can arise in identifying carers when they do not conceptualise their role in this way, but also points to the reality that much spousal care – particularly in later life – has at least a component of co-dependency and mutual support. However, when the nature and quality of the spousal relationship is fundamentally changed by the circumstances of caring (such as in caring for a partner with dementia), carers may experience particular stress and care burden (Davis, 2011). The quality of the care relationship, and the perception of mutuality, are important predictors of people’s capacity to sustain caring (Shim, Landerman, & Davis, 2011).

- 4.47 How older spousal carers with disabilities and impairment experience caregiving has been relatively neglected in research, but the complexity of spousal care is apparent:

“From a demographic perspective where people are living longer, older people and especially older people with disabilities might represent the bulk of society’s informal caregivers, and they need to be further recognized and acknowledged not only as receivers of social care but also as providers of invaluable care.” (Torge, 2014)

- 4.48 Understanding the meaning attached by couples to mutual caregiving and why it may be preferable to other sources of help requires careful and flexible response, as Torge also comments:

“..health care professionals need to be sensitive to the dynamics of the couple relationship and carefully explore the couple’s preferences for how formal support can best be provided in ways that honour and sustain the integrity of the couple relationship.” (Torge, 2014 P.221).

- 4.49 As with any caring dyad, spousal carers cope in different ways and despite the ‘burden of care’ that many undoubtedly experience, caring can also bring satisfactions and enable people to continue to value what is often a relationship of very long-standing. How people cope with the demands of their role; how they develop resilience, and what differences there are between older spousal carers and others are areas where further exploration is needed (Greenwood & Smith, 2016).

- 4.50 Older carers are typically coping with more complex health needs in the person they support, often with multiple comorbidity, and in addition are more likely to also have their own health and disability challenges.(McGarry & Arthur, 2001). Older carers are more likely to be caring for someone with dementia, and:

“it is very likely that they carry out a wide range of care-giving activities including health care and nursing-type activities as well as much care-giving of an intimate or personal nature.” (Pickard, Glendinning, & Shaw, 2000)

- 4.51 Understanding the distinctive characteristics of older carers has implications for the nature and manner of professional support. The ‘choice’ to become a carer, or to continue caring, for example may have little meaning “in the context of relationships characterised by lifelong obligations and reciprocity” (Pickard et al, 2000, P.742). The sense of obligation is also likely to mean that older carers are reluctant to ask for help or to admit that they are struggling to cope. Simultaneously, services are rarely offered to people proactively with the result that older carers are too often left to cope with highly demanding and difficult personal care tasks. Lack of breaks from caring are also likely to lead to a crisis in care-giving but older carers are unwilling to make use of respite services that are institutional in style, and which they find unacceptable (Pickard & Glendinning, 2001).

- 4.52 Not all older carers are providing support to a spouse or partner, and with longer life expectancy, ageing carers are also to be found with life-long responsibilities for their disabled adult children (particularly for people with learning disabilities), and often with no plans for the future despite carers being aged in their 70s or older (Bowey & McLaughlin, 2007). Perkins and Haley point to this “unique population of carers” distinguished by the duration of their caring, alongside concerns about their own health status and ageing, and about the future care of their son or daughter after their own death or incapacity (Perkins & Haley, 2013). Interestingly, as with spousal carers there is some evidence of mutual care and support and:

“The roles of carer and care recipient may evolve over time and become rather blended as both carer and care recipient age.” (Perkins & Haley, 2013, P.342)

- 4.53 The finding of reciprocity in both emotional and tangible support in dyads of carer and care recipient existed irrespective of the severity of learning disability, and was a “potentially promising predictor of carer wellbeing.”

Gender and Care

4.54 Many aspects of gender and care arise in relation to employment and attempts to balance caring responsibilities and paid employment, and these issues are explored elsewhere in the paper. Here we consider changing understanding of gender and caring more broadly. Caring has long been seen as activity predominantly undertaken by women, particularly by those in middle age, and that women commit more time to caregiving than men. While the predominance of women as carers is well documented and understood, the significance of men as carers in later life has received less attention, but among those aged over 70 a higher proportion of men are carers, and they are more heavily time committed to care-giving (typically for a spouse) (Dahlberg, Demack, & Bamba, 2007).

4.55 Milne and Hatzidimitriadou's exploration of older husbands as carers highlights not only the existence of this often-overlooked group, but the fact that there are clear differences in the experiences of older men and women in being a carer and the meaning of caring, such that older husband carers are "widely regarded as wonderful" (Milne & Hatzidimitriadou, 2003a).

"Caring offers older husbands considerable benefit, status and self-esteem, and accords these men both a role and a vehicle for reciprocity within marriage and an expression of commitment to their wives." (P.402)

4.56 Eriksson et al described a slightly different scenario from research in Sweden that explored adult daughters' perceptions of the caring undertaken by their fathers. Daughters apparently valued their fathers' softer side and the care that they provided to a spouse, but they also drew attention to the cost that such feminisation had for their fathers in their wider social relations, particularly with other men, and the contradictions that caring and gender role identity produced (Eriksson, Sandberg, Holmgren, & Pringle, 2013).

4.57 Analysis by Del Bono et al challenges the relationship between gender and caring in older life and concludes that the apparent difference is due to differences in marital status (Del Bono, Sala, & Hancock, 2009) Moreover, this is likely to change in the future:

"In particular, the share of single and especially of divorced or separated women will increase substantially, while the percentage of married men will decrease. These trends imply that gender differences in the provision of care which are mainly due to

differences in marital circumstances are likely to be significantly reduced or disappear altogether.” (P.272)

- 4.58 A further dimension of gender and care concerns care in the context of LGBT relationships, which until recently has been largely absent from the care discourse. Manthorpe (Manthorpe, 2003) points out that “certain relationships have dominated discussions about informal carers and those receiving care”, and in particular the early focus was on the model of the ‘spinster daughter’, then moved to the ‘sandwiched’ adult woman with demands both for her children and her aged parents/in-laws, and latterly attention has moved to spouse care:

“The family is the linking relationship between all such models, whether constructed by marriage or blood tie. Other relationships remain neglected, both conceptually and in terms of practice in community care.” (Manthorpe, 2003 P.753)

- 4.59 The formation of the Lesbian and Gay Carers Network of the Alzheimer’s Society arose in the 1990s from the efforts of one gay man caring for a partner with a diagnosis of pre-senile dementia who had found images of caring did not reflect his own experience (Newman, 2005). The needs of older gay and lesbian people have also been largely overlooked in the wider nursing literature; indeed, research which has been undertaken has highlighted people’s difficulties in being accepted as ‘next of kin’, and being excluded from crucial discussion and decision making in end of life care (Price, 2005).

- 4.60 Willis et al (2011) undertook a scoping study of the territory and pointed to the “negligible amount of social work and social care research” specifically concerned with issues for LGBT carers. Such previous work as there has been has focused largely on specific care needs, such as for carers of people with dementia or with AIDS/HIV (Willis, Ward, & Fish, 2011). Areas identified for further investigation include the following:

“Prime issues include the heteronormative assumptions encountered from health care professionals about sexual subjectivities and relationships; the absence presence of LGBT carers in organisational data collection and monitoring; and the differing kinds of care practices demonstrated within transgender communities in comparison to more traditional understanding of caring relationships.” (Willis et al, 2011, P.1317)

Ethnicity and Carers

- 4.61 A further aspect of variation in the diverse carer population concerns ethnicity, and as with some other variables, this is a dimension that is often regarded as 'hidden' or where carers are deemed 'hard to reach'. Caring occurs in all communities and relationships, and while there are shared and common features in the experience of all carers, there are also distinctive elements in the experience of different BME communities, and reflecting different cultural and social expectations and assumptions. For example, there are distinctive issues around language and communication needs; culturally appropriate services and support; and the barriers created by implicit and explicit racism and prejudice (Katbamna, Ahmad, Bhakta, Baker, & Parker, 2002).
- 4.62 Work undertaken by Carers UK has also highlighted the fact that Black Asian and Minority Ethnic (BAME) carers face the same challenges as all carers,
- "but also face additional barriers, for instance cultural barriers, stereotypes and language which can increase the chances of poorer health, poverty and social exclusion."* (Carers UK, 2011)
- 4.63 Others similarly emphasise that while support for carers generally is inadequate,
- "the experience of black and minority ethnic carers tends to be compounded by structural disadvantage and the marginalisation of 'race' equality within social policy."* (Gregory, 2010)
- 4.64 At the same time, black and minority ethnic carers are not a homogenous group, and there is considerable diversity between and within communities. Greenwood et al emphasise that there are both shared and unique experiences, and reasons for not using services for example may apply to many ethnic groups, including the white majority (Greenwood, Habibi, Smith, & Manthorpe, 2015)
- 4.65 Much British research on the experience of people with conditions such as dementia has focused on people from white British backgrounds, and taken little account of how family members of different minority ethnic groups manage the situation or access services. Research which has been done has highlighted challenges around poor cultural and language awareness in services, and in part this is a reflection of wider equalities issues in health and care services (Forbat & Nar, 2003).
- 4.66 Assumptions about the patterns of kinship networks within and between generations in minority ethnic communities may tend towards the view that 'they look after their

own', but this has come under critical scrutiny from a range of research. Exploration of informal support in South Asian communities, for example found carers no more likely than those from other communities to be supported by wider kinship and social networks (Katbamna, Ahmad, & Bhakta, 2004).

"In fact, the findings challenge the pervasive assumption and stereotype that South Asian people live in self-supporting extended families, and therefore, that the support of social services is largely unnecessary." (P.404)

- 4.67 The disadvantage of carers in these communities is further compounded when knowledge about and access to care and support services *"may be additionally limited in comparison to carers from the majority community"* (P.405).

- 4.68 Lawrence et al's study of attitudes and support needs of Black Caribbean, South Asian and White British carers of people with dementia in the UK identified 'traditional' and non-traditional' caregiver ideologies (Lawrence, Murray, Samsi, & Banerjee, 2008). A traditional ideology was associated with seeing caring as 'natural, expected and virtuous', and in turn, this informed feelings of fulfilment in caring, experience of strain, and attitudes towards support services. The authors found that the majority of the South Asian, half of the Black Caribbean, and "a minority of the White British" participants had a traditional ideology. The implications of such findings for support will vary depending on traditional/non-traditional ideologies. For example, Lawrence et al argue that the former may need help to see services as supporting not substituting for their own input, and to understand that professional help is not needed because of a failure to fulfil family responsibilities, while carers with non-traditional ideologies may find fewer intrinsic rewards in caregiving and may attach greater value to being able to remain in employment and protect other social roles.

- 4.69 The meaning and significance of mental illness and physical disability can be very different in some cultural and minority ethnic communities. Research into the experience of carers of people with dementia in Asian communities, for example, has underlined the lack of knowledge about dementia, and a view that it is part of ageing rather than a specific condition, but something which is also seen as stigmatising and shameful (St. John, 2004):

"The illness is not conceptualised as an organic disease associated with old age, but as a result of it. This affects how families understand the needs of those with dementia and their carers. The project brought to light an almost universally negative perception

of dementia sufferers' behaviour, and that in the early stages symptoms are viewed as a normal part of ageing and therefore not treatable.” (St John, 2004, P.23)

- 4.70 Similarly, Koo has drawn attention to the relative dearth of research on British Chinese carers, and in relation to carers of people with depressive illnesses he has identified the centrality of the family unit and collectivism (Koo, 2012). These values may partially account for the low take-up of support services among British Chinese carers, but compounded by views about mental illness and stigma:

“The carers explained their reluctance to accept outside support by visiting nurses, even when the former felt overwhelmed by their responsibilities, through a profound connection between the obligation to serve ill family members and essentialist ideals of being human and maintaining ‘social dignity’ for the patient and family (...) beyond the stigma of mental illness perceived from others, and by the self, an additional shame associated with failing to fulfil an expectation within the prioritised family unit establishes a barrier to admitting the need for external support that is too high for most carers to overcome.” (Koo, 2012, P.1151)

- 4.71 Somerville’s study of Bangladeshi family carers’ experience of palliative care also drew attention to the sense of family duty “to the point of declining help”, and also underlined the isolation experienced by carers often lacking wider family members and networks in the UK (Somerville, 2001). Furthermore:

“The findings of the study not only highlighted the importance of family ties, but the additional anxiety these families experienced at an already difficult time, because of the problems they had obtaining visas so that family members could visit their dying relative.” (Somerville, 2001, P.245)

- 4.72 Given the unwillingness of these carers to complain or to ask for help Somerville argued that nursing staff need to be sensitive to the particular stresses they face and able:

“to act as the families’ advocate in obtaining increased support and in reassuring them that they do not have to struggle alone.” (Somerville, 2001, P.247)

- 4.73 A further aspect of ethnicity and care concerns the relationship between care and migration within the European Community. In view of the current position of Britain following the 2016 the referendum to leave the European Union, these considerations are particularly current. Work undertaken by Ackers, for example, argues the case for

an evidence-based approach to European policy making “grounded in a more detailed understanding of the complex and fluid relationships between mobility and care” (Ackers, 2004).

- 4.74 Ackers’ analysis of the relationship between care, paid work and mobility presents a picture that is “highly complex, often unpredictable, and constantly under negotiation.” Families can be widely distributed across EU countries, and the rate of international partnering within the population of mobile EU nationals “typically result in a significant and complex dispersal of family relationships across international space” (P.391). Ackers also draws attention to the population of mobile younger retired people, and their role in providing care to older relatives, adult children and grandchildren:

“These concerns remain completely absent from international migration theory. Very many of these people move at some point in time, not only to access but in order to provide unpaid care (...). Most migrants will be under pressure or wishing to move in order to provide care at some point in their lives (...) The only solution that responds directly to the unpredictable and fluid contours of the life-course and recognises the importance of care-giving to European society lies in a more inclusive approach to citizenship.” (P.392)

- 4.75 The implications of this in a post-Brexit world have not even begun to be explored.

Hidden Carers

- 4.76 The nature of caring means that almost by definition much of it is hidden from view and takes place behind closed doors; nonetheless, some caring relationships are less visible – or expected – than others. The terminology of ‘hidden carers’ is widely used to refer to various phenomena. On the one hand, it can refer to carers failing to identify themselves as such (and often not perceiving themselves as ‘carers’ but simply as doing their duty to a parent, partner, child or other relative) and thereby remaining hidden from or unknown to services. It is also frequently used to describe the challenges of identifying and locating specific sub-sets of carers – most often including elderly or disabled carers; young carers; rural carers; men; carers from black and minority ethnic groups, and carers in other groups that may be ‘below the radar’, including those in LGBT relationships. These carers can remain hidden because of a lack of awareness on the part of health, education, care and support services that fail to identify these carers as they are not attuned to recognising them or have limited

cultural awareness of their existence. For carers, this lack of recognition means they fail to have access to support and services that may assist them in their multiple roles.

- 4.77 Good practice guides and resources issued by various organisations have focused on the importance of raising professionals' awareness and understanding of carers and their needs. For example, the RCGP and the Princess Royal Trust for Carers (subsequently the Carers Trust) issued an 'action guide' for GPs and their teams, based on the underpinning belief "that patients benefit when carers are treated as partners in care" (RCGP & Princess Royal Trust for Carers, 2008). This recognises both the information and support needs of carers in their own right, as well as the expertise and knowledge the carer brings regarding the person they care for. The guide also addresses the HR aspects of this carer awareness – realising that there will be people with caring responsibilities within the primary care team.
- 4.78 Similar good practice and principles have been identified for other groups of hidden and marginalised carers. Gray and Robinson, for example, focus on the situation of young carers of people with mental health problems (Gray & Robinson, 2009).

"Many professionals from health, social services and education are not fully aware of the challenges facing young carers for people with mental health problems. An ethos of listening, responding and dialogue must be developed, in conjunction with more partnership working and training on young carer issues, if services and young carers are to work together effectively." (Gray & Robinson, 2009, P.105)

- 4.79 Greenwood et al's exploration of GPs' awareness of carers underlined the gap between aspiration and reality (Greenwood, Mackenzie, Habibi, Atkins, & Jones, 2010). Despite GPs recognising the importance of supporting carers, and believing they should be pro-active in doing so:

"they frequently lack confidence and training and sometimes knowledge to do it effectively. Key issues highlighted include the identification of carers – some GPs are aware that they are not identifying all carers in their practices and would like to be guided on how best to do this. Few services are currently being offered by general practices specifically for carers despite GPs' belief that carers want their support. The few carers' registers reported here by the GPs is all the more surprising given the financial incentives to have them." (Greenwood et al, 2010, P.104)

- 4.80 The authors point out that the potential significance of GPs to supporting carers has long been identified, and although GPs in their study agreed that carers should be

partners in care, “little progress seems to have been made”. While setting up carers registers may be an important first step, they argue that without time and knowledge to offer support to carers thus identified “raising expectations may be detrimental.” Increasing the number of carers leads or ‘champions’ within primary care teams is suggested as one way forward, but recognising the effectiveness of this role requires evaluation.

- 4.81 Carduff et al emphasised that barriers to carer identification are two-fold – those that stem from carers themselves, and those arising from services (in their research focusing on primary care). This means that strategies similarly need to address both dimensions, namely supporting carers to self-identify and request help, and also encouraging services to be proactive in seeking out carers (Carduff, Finucane, Kendall, Jarvis et al., 2014). However, as we explore further below, self-identification for carers is not merely about raising awareness. The identify of carer may be viewed with reluctance or perceived as inappropriate for many reasons, not least because of the complex emotions that may be involved, and the nature of caring which is embedded within a normative relationship.
- 4.82 Knowles et al have recently proposed that carers of people with long term conditions – LTCs - (such as coronary heart disease or kidney disease) might also be considered as actual or potential hidden carers (Knowles, Combs, Kirk, Griffiths et al., 2016). Increasingly, long term conditions are approached through self-management and the authors argue that this:

“may risk creating a new group of ‘hidden’ carers who are providing substantial support which is less stereotypically recognisable as ‘caring work’.” (P.211)

- 4.83 In particular, qualitative interviews with carers supporting people with LTCs revealed that they did not perceive themselves as carers because of comparisons they made with what they understood other carers did, and therefore not seeing the legitimacy of their own caring that was more about emotional support than physical. There was also a level of conscious rejection of the identify of carer because of the inference that this would identify the person they supported as the dependent and ‘cared for’, while they were trying hard to maintain a sense of normal life and identity. The failure to self-identify meant that carers failed to recognise or access support that might be available to them “despite the substantial emotional and practical responsibilities undertaken.”

5 Scoping the Knowledge: b) Type of Care

- 5.1 Thus far this section has provided an overview of the variables that describe the carer population. It is not possible to address each dimension in detail, and that is not the intention. Rather the purpose is to highlight the features that are especially striking or notable. The same approach is adopted in addressing the other categories of themes, and we turn now to consider briefly the type of care provided and for whom.
- 5.2 As well as carers being extremely diverse – as we have explored above – who they are providing support to, and the reasons for needing care, are similarly varied. However, in the review the most frequently identified types of care – in descending order - are associated with:
- Older people
 - Dementia
 - Mental health
 - End of Life
 - Cancer, and
 - Long Term Conditions (including neurological conditions).
- 5.3 Less frequently identified are references associated with caring for people with multiple and complex needs; for stroke survivors; learning disability, and AIDS/HIV. None of these groups is mutually exclusive and there are considerable areas of overlap within and between categories, particularly between dementia and older people, but also between older people and learning disabilities, and mental health. Given the significance of both caring for parents and of spouse care, it is not surprising that so much of the review materials relate to dementia and older people.
- 5.4 The great majority of items and references in the review are concerned either with understanding and quantifying the impact of care, or with the role and contribution of support and services; both categories are explored more fully in the remainder of the paper.
- 5.5 While all caring situations are different, and caring for people with different conditions and needs also produces distinctive demands, there are also features of caring that are widespread or common across all types of caregiving. Carers may be involved in providing help with all aspects of daily life, including in practical terms; with personal care; companionship; assistance with shopping and housework; help in managing

services; managing finances and benefits; helping with paperwork, and giving medication. The impact of care and the 'burden' of care (see below) typically refers to the emotional and psychological costs and stresses of caring.

- 5.6 Caring is not without conflict, and tensions in relationships may arise particularly around questions of identity and autonomy. Henderson, for example, has explored the experience of 'care' in mental health and highlighted the conflicting needs of carers and users of services (Henderson, 2002). She comments that:

"Models of care developed in relation to older people or physical disability do not transfer easily to mental health, perhaps because the issues surrounding personal care do not seem to apply in this area." (P.37)

- 5.7 One characteristic of some mental health conditions – such as bi-polar disorder – is their intermittent and fluctuating nature, and people may remain well for long periods. "they are not in a permanent state of caring or being cared for." And, Henderson argues this changing picture "challenges traditional discourses on care" (P.38).

- 5.8 We have emphasised previously that care takes place within a relationship, and there can be particular difficulties in a relationship which may not fit easily in a care system in which treatment can be imposed without consent:

"there may be disagreement within a relationship about diagnosis and therefore the need (or lack of it) for care. This may or may not be at odds with wider definitions and expectations in professional and social relationships. Many professionals assume that someone's partner is their 'carer' and work with them accordingly. 'Carers' are assumed to be on the side of the professional. For some people this is an identity they aspire to, and indeed throw themselves into. For others, an identity of 'carer' bears no similarity to their own construction of their role within a relationship." (Henderson, 2002, P.44)

- 5.9 The role of a carer within mental health policy may occupy a particularly ambivalent status, especially when the carer is 'professionalised' by services and is seen as the expert in 'caring for' the person with mental health needs. Indeed, Henderson argues that this can have a 'devastating impact on partnerships' and relationships.

- 5.10 Keywood similarly identifies overlapping and at times conflicting roles for carers associated with mental health law reform and incapacity decisions (Keywood, 2003). Whether carers can simultaneously act as advocates, gatekeepers and proxy decision-

makers requires some significant compromises and potentially creates situations in which these multiple roles are incompatible.

- 5.11 A similar discourse is evident in international literature. Goodwin and Happell (Goodwin & Happell, 2006), for example, have presented a critique of:

“the tendency of Australian Government policy to present consumers and carers as a collective with an apparent assumption that these needs can be met by similar initiatives” (P.136)

- 5.12 Rather, they argue there are at times ‘conflicting agendas’, and that nursing staff experience particular conflict when trying to balance the desire of carers to be fully involved and given appropriate information, with the preferences of the consumer “to whom they owe a primary duty of care.” They conclude:

“For the goal of current mental health policy to increase consumer and carer participation to be realized, it is crucial that policy-makers cease to view the interests of the two groups as synonymous.” (P.141)

- 5.13 Similar tensions and potential conflicts have also been identified in the learning disability field. Williams and Robinson identified three major sources of conflict or disagreement between carers and a family member with a learning disability centred upon: the need for a break from caring; the need to speak for their relative; and concern over behaviour (Williams & Robinson, 2001). There is also long-standing recognition of the difficulties that can arise in transition planning for young adults with intellectual disabilities. Pilnick et al identify the tensions between carers’ concerns for their adult child, and indeed for their own lives, versus aspirations for choice and self-determination (Pilnick, Clegg, Murphy, & Almack, 2011).

- 5.14 The tensions between care and protection are also increasingly recognised in relation to caring for people with dementia. Askham et al identify three kinds of social relationship likely to be found when people with dementia are cared for at home: custodial care, an intimate relationship and home life (Askham, Briggs, Norman, & Redfern, 2007).

“Homes are not total institutions, and people with dementia are not inmates. But living at home with a person with dementia brings the challenge of how to preserve home-life and an intimate relationship alongside providing care and custody (...) Living with a person with dementia is a complex balancing act that is difficult to sustain. It is in

constant danger of slipping towards the practices and life of a total institution, and is fraught with challenging problems for both carers and the people with dementia.” (P.21)

- 5.15 A related debate is emerging around the use of telemonitoring, particularly in caring for people with dementia, and Draper and Sorell for example, have drawn attention to the ethnical tensions that can arise (Draper & Sorell, 2013):

“The perspectives of carers and users may be increasingly difficult to keep in balance the more telecare enables information and control to pass from user to carer (...) For telemonitoring to qualify as care, it must be integrated into a care relationship which incorporates personal contact, and which is personalized through negotiation to take account of the interests and autonomy of all involved in the caring.” (P.372).

- 5.16 Ganyo et al have similarly identified ethical concerns around the use of telecare for remote monitoring and surveillance, including falls detection, highlighting issues relating to autonomy, privacy, benefit and the use of resources (Ganyo, Dunn, & Hope, 2011). Godwin has argued that the complexity of using assistive technology (AT) in dementia care necessitates individualised, person-centred ethical assessment (Godwin, 2012). White and Montgomery’s exploratory study of the ethical issues experienced by carers in making decisions about electronic tracking to manage wandering behaviour by people with dementia, found carers prioritising safety over liberty and autonomy (White & Montgomery, 2014).

“The study suggested that a decision to use electronic tracking partly reflected a need for carers to have reassurance, space from the person, and time out from the caring role. This raises questions about who the technology is for. Careful consideration is warranted of how it may be used in a way that reflects the best interests of the person with dementia as well as the needs of the carer.” (P.228)

- 5.17 It is important to recognise, as the discussion above has explored, that the interests and preferences of carers and those they care for are not always identical and – at times – may be contradictory or at least in tension with one another. This is likely to be a feature of all caring relationships, regardless of the reasons for care, but the dissonance is more apparent in situations where there is some cognitive impairment or mental illness. Recognising the interdependencies of the needs of carers and those they care for in a dyadic relationship requires the areas of tension and conflict to be acknowledged and addressed.

6 Scoping the Knowledge: c) Impact of Care

- 6.1 As the charts in Section 3 demonstrated, examination of the impact of care is the single largest category of all analyses and represents almost 40 per cent of all themes identified. Caring exists in multiple forms, and involves people in different relationships, supporting people with distinctive and specific needs which make every caring situation distinctive. Nonetheless, there are many aspects of caring which are common to all or most carers. As many commentators point out, caring is a complex experience that can impact on all aspects of a person's life. Identifying that there may be physical, emotional or psychological *impacts* is often referred to using the shorthand of the 'burden of care' and there is a considerable literature that addresses this topic. In adopting the term here, we are mindful of the potentially pejorative connotations this may have, but that is not the intention. Rather, it is to recognise that there *are* many ways in which caring is demanding, arduous, stressful and costly in physical and psychological wellbeing as well as in practical and personal terms. As O'Neill has remarked, it may be more meaningful to refer to "burdensome aspects of care" rather than to repeat the trope of carer burden (O'Neill, 2015). It is also apparent that the concept of burden is more complex than it first appears and that there are both objective and subjective dimensions.

Burden of Care

- 6.2 Various assessment tools to measure carer burden have been developed for use in both research and clinical or practical support contexts. Charlesworth et al (Charlesworth, Tzimoula, & Newman, 2007) point out that some of the early measures in particular have been criticised for various shortcomings:

"theoretical incoherence; poor psychometrics; an implicit assumption that carers' experience of burden is explained by levels of impairment of the care-recipient; being 'patient-centred' rather than 'carer-centred'; lacking sensitivity to change and using summary scores that mask underlying sources of burden." (P.218)

- 6.3 More recent measures such as the Carers Assessment of Difficulties Index (CADI) are generally seen to provide robust measures of the multi-dimensional nature of care burden, reflecting both the frequency of potentially stressful events (objective burden), and the carer's perception of their stressfulness (subjective burden). McKee et al argue that "family care is more complex than a burden model would suggest", and that

assessment instruments therefore need to be able to reflect this complexity (McKee, Spazzafumo, Nolan, Wojszel et al., 2009). Development of work on the CADI has subsequently produced related indices of the CASI (Carers Assessment of Satisfaction Index) and CAMI (Carers Assessment of Managing Index). McKee et al undertook research with carers in the UK, Italy and Poland evaluating the use of all three indices. The subscales were found to have divergent associations with demographic and caregiving characteristics, and the CASI subscales had fewer significant associations:

“Suggesting that satisfactions gained from caregiving might be more personal and idiosyncratic than coping strategies or burdens, and therefore not so easily explained by gross characteristics of the person such as gender, or obvious characteristics of the caregiving situation, such as co-habitation status or duration of caregiving.” (McKee et al, P.262)

- 6.4 Use of the three indices is seen by McKee et al to have much potential as a research instrument and as an assessment model in practice settings. Together the three indices may have a particular contribution in “expanding practitioners’ understanding of the complexity of caring situations” (P.263). The importance of cultural factors on mediating caregiving satisfactions is a further variable identified by McKee et al, and also highlighted in various other studies (Chan & Chui, 2011). Sequeira’s study of satisfaction and burden among Portuguese carers (using the CADI, CAMI and CASI indices) found carers of people with dementia more vulnerable than those caring for people with physical needs only, due to higher levels of burden (associated with higher levels of difficulty and reduced satisfactions) (Sequeira, 2013).
- 6.5 Deeken et al carried out a review of instruments developed to measure carer burden; needs and quality of life – these three categories have largely been developed separately despite there being considerable overlap (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003). A recurrent theme identified in their review reinforces findings from other studies, particularly in this respect:
- “the demands placed on caregivers, and their response to those demands, are not simple. Caregivers’ responses do not directly correlate with caregiver demographic characteristics or with patients’ physical or psychological health status.”* (P. 947)
- 6.6 The development of instruments to assess dimensions of carer burden can have multiple applications. While there is clearly an important contribution to theoretical and research understanding, as Deeken et al comment, there is a relative dearth of studies

using instruments to test outcomes linked to interventions and their effects on carers. If assessment instruments are to be robust and useful to both researchers and clinicians, Deeken et al argue:

“it is critical that the refinement of clinical assessment tools and studies about caregiver interventions must proceed so that professionals will know when and how to intervene to assist the overly burdened caregivers of their patients.” (P.950)

- 6.7 Much of the ‘burden’ focus in the literature and carer discourse comes from exploration of those caring for people with dementia who are generally found to experience higher levels of burden. This might be expected given the characteristic symptoms that typically accompany dementia including: behavioural disturbance and distress, confusion and cognitive impairment, wandering, incontinence, and physical dependency. Any or all of which are likely to prove extremely stressful. However, Campbell et al’s multiple regression analysis found that a person’s level of cognitive function; the level of help required for everyday living; behavioural and psychological symptoms were *not* significant contributors to carer burden. Indeed, it was not objective severity variables that impacted on burden, but subjective interpretation and experience of the carers (Campbell, Wright, Job, Crome et al., 2008)

“From the analysis it was shown that the strongest predictor of caregiver burden within the model is the caregiver’s sense of ‘role captivity’.” (P.1082)

“The study has shown that it is not so much the ‘objective’ load on the caregiver that leads to burden but more importantly it is in how the caregiver perceives this load in terms of their previous relationship with the patient, their own confidence and efficacy in the role and the time they have to develop and sustain their sense of self.” (P.1083)

- 6.8 The implications of the study for practice and for carer support challenge assumptions about how carers of people with dementia experience burden, and underline the issues to explore with carers in assessment and to ensure an understanding of individual circumstances.
- 6.9 Rinaldi et al observe that it is often difficult to distinguish the factors that contribute to burden and to distress, and undertook a large study in Italy (involving 419 patients with dementia and 419 matched carers). Using the Caregiver Burden Inventory that assesses both objective and subjective burden, and found that older carers (aged over 70) and spouse carers – more than adult child carers - were particularly likely to

experience high burden (Rinaldi, Spazzafumo, Mastriforti, Mattioli et al., 2005). As they observe:

“This is so probably because the spouse often suffers from age-associated chronic illnesses and providing care is more difficult than for an adult child when care needs increase (...) Dementia can undermine the marital relationship, so that reciprocity can be lost.” (P.173)

- 6.10 Bruvik et al also explored whether the coping of carers accounts for differences in their experience of burden. Carers with a high external locus of control (LoC) – that is, they believe that what happens is due to factors beyond their control – experienced more burden than carers with a greater internal LoC who believed they were in control and could use more active coping strategies and problem solving approaches (Bruvik, Ulstein, Ranhoff, & Engedal, 2013). Perception of burden, and interventions that can reduce the perception, and increase the satisfactions of caring would therefore seem to be of particular importance (Sequeira, 2013)

- 6.11 De La Cuesta-Benjumea’s qualitative research with women in Spain providing care for relatives with advanced dementia has drawn attention to the importance in coping strategies of removing oneself from the caring identity, and ‘taking leave’ from the life of care-giving (De la Cuesta-Benjumea, 2011):

“A close examination of the data shows that when caregivers act upon other identities such as being a grandmother, a wife, a mother, or a friend, they attain rest. Thus, it is of little relevance what the caregiver actually does or where she is, but it is fundamental who she is in her relations to others and the social space that she occupies.” (P.1794)

- 6.12 Such findings add insight to the nature of respite and the “importance of connecting with other selves for the relief of burden.”

Satisfactions of caring

- 6.13 One of the variables that can impact on subjective experience of burden concerns the satisfactions that may be derived from caring. Iecovich, for example, refers to the “gain and strain” theory of caregiving, and points out that while burden has been widely investigated, less attention has been directed towards satisfactions (Iecovich, 2011). If increasing satisfactions from caring can reduce carer burden, there would seem to be particularly valuable insights gained from understanding the interplay between

these dimensions. Iecovich explored 335 dyads of care recipients and their adult children who were primary caregivers in Israel, using measures of caregiver burden, satisfaction and quality of relationship. The study found that quality of relationship had the most significant impact on both caregiving burden and satisfaction.

- 6.14 Consistent with other studies, Iecovich found both burden and satisfactions to be largely subjective experiences rather than a reflection of objective difficulty or severity of caring demands, but “quality of relationships was found to affect both of them more than other variables” (P.586).
- 6.15 Cohen et al’s exploration of positive aspects of caregiving found that carers who identified more positive feelings “were less likely to report depression, burden or poor health” (Cohen, Colantonio, & Vernich, 2002). Negative consequences of caring are known to be associated with poor outcomes (including mortality) for the carer, and increased likelihood of permanent institutional admission for the care recipient. Cohen et al suggest that carers reporting more positive aspects may therefore “be buffered from these negative consequences for themselves and those they care for” (P.187). As with so much carer research, however, longitudinal analyses are required to understand the effects of satisfactions on caring, and which positive aspects might be more important than others, “as we are not able to establish causality with our cross-sectional data.”
- 6.16 Pinquart and Sörensen’s meta-analysis refers to positive aspects of caring as the “uplifts” derived from such aspects as feeling useful, appreciating closeness to the person being cared for, and taking pride in the ability to handle crisis situations (Pinquart & Sorensen, 2003). They conclude that because behaviour problems are the most associated with carer stress and burden,

“interventions that reduce behaviour problems of the care recipient and increase caregivers’ skills in handling behavioural difficulties are needed.”

“Second, because we did not find much evidence that perceived uplifts of caregiving may be eroded when the objective level of stress increases, psychological interventions might also focus on strengthening perceived uplifts of caregiving, for example by cognitively restructuring caregiving perceptions, strengthening positive aspects of the CG-CR relationship, and promoting appreciation by other family members.” (P.122)

- 6.17 Sequeira's findings that carers of people with dementia experienced greater burden also underlines the significance of behavioural factors. As with other studies, the author concludes that caring is associated with a set of stressor agents which are:

"mediated by the relationship of providing care and which may result in a greater or lesser degree of burden and/or caregiver satisfaction." (P.498)

- 6.18 Jensen et al comment on why it is important to direct attention to the benefits and satisfactions of caring, recognising that this is complex territory and a great deal of research has been focused on burden as 'the primary or only experience of the caregiver' (Jensen, Ferrari, & Cavanaugh, 2004):

"Therefore, the tendency to view caregiving in a negative light exists. Indeed, most studies on elder care have concentrated on burden exclusively, overlooking potential benefits caregivers perceive. Highlighting burdens affiliated with elder care, without acknowledging potential benefits provides an incomplete picture and may be detrimental to aging families. It can set up negative expectations, self-fulfilling prophecies and limit our conceptual treatment of caregiver adjustment and satisfaction." (P.88)

- 6.19 Lyonette and Yardley (Lyonette & Yardley, 2003) found that while carer stress is independently associated with a poor relationship with the person cared for (in their study, older people), "better relationship quality and greater intrinsic motivations to care are the most significant predictors" of carer satisfaction. However, unravelling the personal aspects of predictors of stress and satisfaction is complex, as they also note:

"Carers who report high carer stress may be likely to report a poor quality of relationship as a consequence of stress, rather than because the poor quality of relationship caused their stress. Indeed, there is the possibility that two-way effects characterise all the relationships studied in this analysis." (P. 502)

- 6.20 Many of the other references to 'satisfaction and care' identified in the materials relate to carers' experiences with support and specific interventions, and we will return to this aspect in addressing support later in the document.

Resilience and Coping

- 6.21 How carers deal with the multiple demands of caring raises multiple issues around coping strategies and resilience; how do some carers manage better than others and what variables are of importance? Understanding different coping strategies and how they relate to experiences of 'care burden' is important in identifying how best to support carers and enhancing their own resilience. Conceptualisation of coping strategies in many studies draws on the work of Lazarus and Folkman (1984) who defined coping as:

"constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that appraised as taxing or exceeding the resources of the person." (Lazarus & Folkman, 1984) (P.141)

- 6.22 'Coping' therefore refers to the 'thoughts and acts' that carers bring to solving problems and thereby reducing stress. These coping strategies are usually classified as emotion-focused, and problem-focused; and approach or avoidance. This theoretical framework provided the basis for the later development of the Carer's Assessment of Managing Index – CAMI (Nolan, Keady, & Grant, 1995).

- 6.23 As the discussion above on 'burdens' and satisfactions of care has indicated, this is complex territory of multiple intersecting variables. Grant and Whittel (Grant & Whittel, 2000) comment that:

"satisfactions and stresses among family carers typically co-exist in the midst of enduring and often challenging home circumstances. It seems that the realities with which families are faced are more complex and subtle than at first appears." (P.257)

- 6.24 Their qualitative study reaffirmed that carers use a variety of problem-solving, cognitive and stress-reduction approaches to caring, and as measured using the CAMI these strategies were differentiated by gender, life stage and family structure. The authors highlight both strengths and vulnerabilities in their findings:

"On the strengths side, there is support for the view that families demonstrate considerable resilience in their everyday coping."

However,

"In relation to vulnerabilities, there must be some concerns that lone carers in particular have to rely quite so much on cognitive coping strategies (...) In some important

respects, men appeared to have less mastery over coping than women. They were less self-confident and appeared to find it harder to derive meaningfulness from much of what was happening around them. They frequently sought to distance themselves from the situation by deferring to their female partner or by maintaining interests outside caring.” (P.272)

6.25 Other variables can also influence carers’ coping strategies; Lockeridge and Simpson, for example, explored younger carers coping with caring for a partner with young onset dementia (Lockeridge & Simpson, 2013). There is evidence that younger carers experience greater emotional distress than carers of older people with dementia, and that they experience greater difficulty coping with associated challenging behaviour. However, younger carers have been relatively overlooked in much research into the subjective experience of caring for people with young onset dementia given the much higher prevalence of dementia among older people and their often-elderly carers. Lockeridge and Simpson believe their study to be the first to look specifically at the coping strategies adopted by younger carers to manage changes in their relationship with their partner with dementia.

6.26 The experience of younger carers of people with early onset dementia was similar in many respects to that of carers of older people with dementia, but there were also differences. Lack of public and professional awareness and understanding of young onset dementia increased the carers’ experience of stigma. Typically, carers were motivated to protect their partner from dementia by sustaining their identity for as long as possible (involving denial of dementia and keeping the truth from their partner):

“Younger carers adopted a range of emotion – and problem-focused coping strategies, though useful in the short-term, ultimately led to negative emotional and psychological outcomes both for carers and their partners with dementia.” (P.649)

6.27 Lockeridge and Simpson suggest that the greater understanding of the coping strategies “may lead to the development of specific assessments and interventions for younger carers, in order to improve their psychological wellbeing.”

6.28 One of the features of caring that is common to many situations is that of uncertainty, but this is arguably a particular aspect of caring for people who have experienced strokes. Greenwood et al point out that the suddenness of stroke, the diverse nature of effects, and the unpredictability of recovery often means responses from clinicians are ‘vague’, adding to the uncertainty and stress of carers (Greenwood, Mackenzie,

Wilson, & Cloud, 2009). How do they manage these circumstances? Important aspects of coping strategies appeared to be accepting uncertainty but also recognising the positive aspects of situations; carers who had previous experience of caregiving were more likely to consciously adopt positive coping strategies and to do so at an earlier stage (following routines; taking things slowly; accepting the situation; keeping a sense of humour, and identifying positives).

“Uncertainty is double-edged – it allows carers to cling onto hope that with time, their survivor might make unlikely improvements but at the same time it leaves them in limbo. The common description of ‘living day-by-day’ helps manage this because focussing on the present and on survivors’ improvements provides a framework for carers to enjoy the satisfactions derived from caring whilst avoiding focussing on the future.” (Greenwood et al, 2009, P.131)

- 6.29 Quinn et al’s meta-synthesis of qualitative research on how spouses cope and adjust to caring for a partner following a stroke also highlighted the uncertainty and unpreparedness of carers and their desire for better stroke-related information and practical training to assist them (Quinn et al., 2014). The meta-synthesis identified seven themes relating to how spouses adapt and cope: seeking information; searching for own space and well-being; suffering in silence; putting one’s own needs aside; adapting to a changed role; social support, and hope and optimism.
- 6.30 Different strategies may be employed at different stages in caring, and the authors comment that spouses putting their own needs aside tended to occur early in the caregiving journey, while as time progressed there was a greater refocusing on spouses’ own needs. The authors emphasised the importance of using the meta-review findings to inform clinical practice.
- 6.31 Not all coping strategies are positive; they are a way of responding to difficult situations but may not be productive in terms of creating greater carer resilience or wellbeing. Emotional strategies such as denial come within this category, while attempting to gain control or achieving some degree of acceptance may be seen as more positive. It is also apparent that caring situations are dynamic, particularly in relation to care for people with dementia for example, where the caring ‘journey’ will evolve and change. In such situations, different coping strategies may be required at different points of the journey. Norman et al looked at how people with dementia *and* their carers perceived change, and how they managed that change (Norman, Redfern, Briggs, & Askham, 2004). As the authors comment:

“Cognitive coping strategies are considered in the literature to be less effective than problem-solving strategies. But in our study (...) the ability of carers to perceive caregiving in a different light emerged as essential if they are to cope with the demands of caring for a person with dementia that change over time.” (P.38)

- 6.32 ‘Change’ was thus a major feature of people’s lives, and was generally perceived negatively, but the response of people with dementia and of their carers involved a range of strategies including denial, acceptance, anger or distress. In such ways people “sought to maintain continuity or a sense of stability and security in the face of deteriorating mental function or unpredictable changes in behaviour.” This study did not explore the effects of different strategies on the wellbeing of the carer, but the findings that people have to adapt to change which can require “all their ingenuity and skill to manage” is illuminating.

- 6.33 The concept of ‘resilience’ in managing the demands of caring is one that is addressed particularly in the mental health and psychology literature. Donnellan et al adopted a qualitative approach to examine spousal dementia carers’ capacity to be resilient, and the factors that facilitate or impede them (Donnellan, Bennett, & Soulsby, 2015). Their analysis indicates findings on “individual, community and societal levels, which suggest that resilience is a multidimensional construct” (P.938). They conclude that:

“a resilient carer is someone who stays positive in the face of care demands and actively maintains and preserves their relationship and loved one’s former self. Resilient carers have access to and use services such as respite care and may actively engage with innovative schemes that aim to ‘give back’ to others in similar situations. Resilient carers are knowledgeable and well supported by family but especially friends, with whom they share this knowledge. Support group friends share emotional and practical advice and reassurance that may help the carer manage their role better.” (P.938)

Carers and Employment

- 6.34 We have referred at various points in the report to carers who face multiple role demands, and a key dimension of this is the situation of people who are combining caring responsibilities with paid employment. How caring impacts on employment, and the importance of employment in carers lives are important not only on the individual level, but also in wider economic terms. Enabling carers to remain in or return to

employment has been a focus of government policy since the first National Carers Strategy of 1999 and in all subsequent iterations.

- 6.35 Arksey's analysis of carers and the workplace points to double edged nature of combining work and care (Arksey, 2002). Thus, research indicates the positive impact:

"employment provides an income and pension rights, it helps to maintain social networks, it offers a temporary relief from the caring role, it enhances self-esteem, and it offers the opportunity to share concerns with colleagues. It can have beneficial effects on carers' physical health and on their emotional well-being. Carers who are in paid work may be less vulnerable to social exclusion." (P.152)

However,

"Conversely, studies have also suggested that combining work and care can be difficult. The adverse effects on carers include: lethargy, tiredness and lack of concentration; worry about caring responsibilities at work; and stress brought on by trying to manage the often incompatible roles of employee and carer, each with its own pattern of conflicting demands and expectations." (P,152)

- 6.36 For some people managing the essential tension between these push and pull factors can become impossible, leading to withdrawal from the labour market, 'early' retirement, or the adoption of new approaches to employment (such as self-employment) that allow greater flexibility. Arksey's analysis unusually brought together the perspectives and experiences both of carers and of employers (much research in this area has focused only on the carers' experience of employment). The findings from both perspectives indicate that there is "no single or simple solution to the issue of supporting carers in the workplace." However, it appeared that women were more likely than men who were carers to have their needs acknowledged, while the research also suggested that there may be a relationship between seniority and opportunities to combine work and care, although the nature of this relationship needed further exploration. Arksey concluded:

"it has been shown repeatedly that caring, and supporting carers, is either absent from or not high on the agenda of many employers." (P.159)

- 6.37 The fact that carers form a relatively small proportion of the workforce may account for the lack of awareness of employers; but given the turnover in the caregiver population,

many more people will experience caring responsibilities at some point in their working lives.

- 6.38 Pickard's review of literature on carers of older people and employment carried out for the Audit Commission commented that most carers of older people are of working age, with almost half being aged between 45 and 64 (Pickard, 2004). Around one quarter of women and nearly a fifth of men aged 45 to 59 are carers, and most of these are caring for older relatives (parents or in-laws). As Pickard comments:

"Although informal carers form a relatively small minority of the workforce at any one point in time, a higher proportion of the workforce is likely to provide informal care at some stage of their working lives." (P.3)

- 6.39 Work commissioned by the Department for Work and Pensions from the Social Policy Research Unit at the University of York explored the "aspirations and decisions of carers about caring, work and pensions" (Arksey, Kemp, Glendinning, Kotchetkova, & Tozer, 2005). Their study (involving a literature review and qualitative research) indicated that most carers wish to work and are reluctant to stop, and that the consequences of giving up work to care can be profound and enduring:

"Many employed carers find it difficult to care at the same time; it appears to become more difficult once people provide over 20 hours of care per week. It is co-resident, rather than extra-resident, carers who face the biggest obstacles. Interrupted or short working careers, or moving from full-time to part-time work, have implications for earnings and subsequent pension entitlements, especially if the caring episode last for many years." (P.1)

- 6.40 More recent evidence suggests that the critical threshold for carers leaving employment may be lower than previous estimates. Pickard et al found that carers providing care for 10 or more hours per week are at risk of leaving employment (King & Pickard, 2013; NIHR School for Social Care Research, 2012). An important finding from the qualitative work by Arksey et al was the complexity of carers' decision making about giving up or remaining in employment. These decisions appeared to be revisited as circumstances changed and reflected the interaction of multiple variables, many of which were beyond the carers' control. At the time of their study it appeared that carers were unlikely to benefit from flexible solutions in their employment:

"most carers appear to have little access to potential carer-friendly workplace policies and practices, and even where they do exist carers can feel unable to take advantage

of them. Most employers, in particular those in the private sector, give little consideration to care-friendly work practices.” (Arksey et al, 2005 P.2)

- 6.41 In recent years there has been increasing attention to research and information gathering around carers and employment matters, not least from the Action for Carers and Employment (ACE National) partnership led by Carers UK, through work commissioned from the Centre for Social Inclusion (Yeandle, Bennett, Buckner, Shipton, & Suokas, 2006), and from the Carers, Employment and Services study commissioned by Carers UK from the University of Leeds (Yeandle & Buckner, 2007). At the same time, these matters have risen up the policy agenda and achieved greater recognition and traction, partly as a reflection of wider family-friendly policy and practice, and greater flexible working.
- 6.42 Yeandle et al identify the ‘multi-faceted rationale’ underpinning these developments, but highlighting in particular the business case, that is, the costs of developing and implementing policies and practices “are considerably outweighed by productivity gains and reduced operating costs” (Yeandle et al, 2006, P.7).
- 6.43 Vickerstaff et al were commissioned by the Department for Work and Pensions in 2008 to undertake qualitative research to examine and understand what employment support is needed for carers to take up, and remain in, employment (Vickerstaff, Loretto, Milne, Alden et al., 2009). The authors commented that their findings confirmed many of the findings from previous studies, highlighting the importance of working for carers in terms of income but also satisfaction. Similarly, the study confirmed the restrictions that caring placed on carers’ opportunities to work, but also provided a more detailed and in-depth understanding of some of the challenges in combining working and caring:
- “Despite unanimous agreement of the importance of work in our study sample, it was clear that combining working and caring was far from easy. The key themes raised were balancing/juggling, stress and guilt. Respondents who worked found themselves constantly having to balance their work requirements with the needs of their cared for person. This was viewed as a source of great stress.” (Vickerstaff et al, 2009, P.121)*
- 6.44 The study revealed the importance of work-related flexibility in facilitating the juggling of competing demands, although the unpredictable nature of caring meant that flexibility – such as in working fixed part time hours – was often less helpful than it appeared. ‘Informal flexibility’ was particularly valued for being more useful, including

being contactable at work which gave carers greater peace of mind and enabled them to focus more effectively on their work. Such informal arrangements however, were predicated on trust between carers and their employers, which was not always the general experience.

- 6.45 The importance of employers being more carer-aware and carer-friendly was underlined. The fact that it was not unusual for carers to keep their caring responsibilities a secret at work was revealing:

“This may be a choice, for example, in order to keep a clear line between work and caring and to preserve a space in which the carer can escape their caring role, but for most it was out of fear of the reaction they would get from their employer.” (Vickerstaff et al, 2009, P.127)

- 6.46 Greater carer-awareness on the part of employers would not only support carers to disclose their situation but would also encourage employers to be alert to signs of potential carer-related stress signs among their workforce:

“Those on long-term sick, or with an emerging pattern of absences may be desperately trying to balance the demands of caring and working and modifications to work patterns might enable them to remain in work.” (P.128)

- 6.47 In 2012 a Task and Finish Group was established between the Department of Health and Employers for Carers to explore ways in which carers can be supported to combine work and care (Employers for Carers/Department of Health Task & Finish Group, 2013). The report from the group set out the belief that supporting carers in this way is “not only a problem, but also an economic opportunity”:

“Supporting people to combine work and care has now become an economic as well as a social imperative. There are significant costs to individuals and families, to employers and business and to the wider economy of carers feeling that they have few options other than to leave work. Some carers choose not to work in order to focus on their caring responsibilities, but many carers feel unable to work because they are not getting the help they need at work, and more still feel they are not getting the help they need from formal care and support services.” (P.8)

- 6.48 The social and economic gains to be made from supporting carers ‘to juggle their work and family lives’ are identified across several fronts:

- *“individuals and families will not face the financial, health and social disadvantage of being outside the labour market;*
- *Employers will realise quantifiable benefits, including retention of skills and experience, increased employee resilience in terms of health, productivity and engagement, and better results through improved performance;*
- *The economy will benefit from improved output at lower cost, higher public revenues and a reduced benefits bill;*
- *There will be a new and previously unrealised opportunity to turn the need for public investment in care services on its head and grow a vibrant, technology-enabled care sector that supports individuals and families, employers and business, while delivering benefits for the whole economy.” (P.9)*

6.49 This would seem to offer a compelling case, but in practice it is evident that translating these aspirations into reality has some way to go. Nonetheless, many employers are recognising the issues and the Task and Finish Group identified case studies from employers showcasing good practice. A programme of pilot projects to explore initiatives supporting carers to remain in or return to employment was funded by a consortium of government departments including the DH, DWP and GEO from 2015 to May 2017. The Carers in Employment (CiE) programme is being independently evaluated by the Institute for Employment Studies, but their report was not yet available at the time of the scoping study. Nine sites were funded and their focus was on one or more of three key areas: information advice and guidance; assistive technology, and employer support and training. The CiE programme has been coordinated and supported by SCIE.

Health Impact of Caring

6.50 So far in this section addressing the impact of caring we have highlighted the ‘burden’ of care, the satisfactions of caring, and the various factors that help carers to cope. Despite the multiple themes identified under the category of ‘Impact of Care’, it is clear that many of them are subsumed within the general focus of ‘burden’. For example, carer depression; emotional and physical impact; psychological impact, and stress and strain are all dimensions of burden. However, it is worth exploring the health impact of caring in more detail, not least because this appeared to be – by some distance – the most frequently identified theme. However, the great majority of these references are, in fact, less to do with carers’ health *per se* than they are associated with the

health of the person cared for. Nonetheless, as much of the literature emphasises, these two dimensions are inextricably linked.

6.51 The health of carers is a concern on many fronts, both because of risk of physical injury (particularly from lifting and handling), and from the psychological and mental health strain of constant and long term caring. Moreover, as we have previously discussed, many carers are older people (half of co-resident carers of older people) and likely to have their own health care needs. Given the increased complexity of conditions that are being managed in the community and in people's own homes, carers are also increasingly involved in carrying out skilled or complex and intimate health care tasks, particularly those relating to continence care.

6.52 The relationship between caring and health is not straightforward. Glaser et al point out that the issue is increasingly about multiple family and work commitments of older adults (i.e. the simultaneous demands of paid employment, caring and other family responsibilities) (Glaser, Evandrou, & Tomassini, 2005). As they comment, there are two opposing theoretical models regarding the impact of multiple roles on physical and psychological health:

"Role enhancement theory suggests that those involved in multiple roles (e.g. spouse, parent and employee) are in better health than those with fewer work and family responsibilities. Role strain theory postulates that multiple roles are associated with poor health outcomes." (P.470-71)

6.53 Using analysis of the longitudinal Retirement Survey Glaser et al found "few statistically significant relationships" between simultaneous role occupancy and health. At the individual level their analyses showed a positive relationship between employment and health, and "mixed results" on the relationship between caring and health.

6.54 Hirst's study of health inequalities and caring used analysis of the British Household Panel Survey and found caring most likely to be associated with inequalities in mental and emotional health. These findings are consistent with other literature that shows carers are more likely than non-carers to report psychological symptoms of stress such as anxiety and depression (Hirst, 2004). However:

"Despite firm evidence for the existence of caring-related inequalities, the findings indicate that most carers do not have additional health problems that could be attributable to their caring responsibilities. Although a substantial minority of carers present poor physical, emotional and mental health, morbidity levels in the carer

population are, in large measure, no different than would be observed if the same people were not providing unpaid care.” (Hirst, 2004, P.18)

- 6.55 Nonetheless, there are substantial variations within the care population and carers providing more intensive support for greater durations report “much higher than expected levels of distress.”

“The findings of this study show the challenge to public health policy that tackling the inequalities associated with caregiving represents. Although the vast majority of carers do not present additional health problems because of their caring activities, the adverse effects of caregiving on carers’ psychological well-being are quantifiable and significant. They are most pronounced around transitions into and out of care and in the more demanding care situations. The risk for psychological distress increases with involvement in and intensity of caring activities.” (P.27)

- 6.56 The greater risk of emotional and psychological distress that exists for a ‘substantial minority’ of carers can be identified. Carers providing at least 20 hours of support a week are at greater risk, so too are women who are carers and caring for a spouse or partner is “particularly associated with additional health problems beyond those that might be attributable to other determinants of health.”

- 6.57 Understanding the health effects of caring is complex, and the evidence indicates that the relationship between caregiving and health impact is neither linear nor causal, and typically the impact is mediated by individuals’ coping skills and resources, as well as by the support they receive more widely. However, the identification of risk factors is important in identifying the groups of carers who are most likely to experience adverse effects.

- 6.58 Certainly, there is considerable evidence that carers report adverse health effects. For example, the partnership of eight national charities involved in Carers Week undertook a survey in 2012 of almost 3,400 carers, exploring the impact of caring on their health and well-being (Carers UK, 2012a).

“The findings of the survey illustrate that for many people caring can impact negatively on an individual’s physical and mental health; 83 per cent of carers stated that caring has had a negative impact on their physical health and 87 per cent of carers stated that caring has had a negative impact on their mental health.” (P.2)

6.59 In particular, carers reported experiencing anxiety or stress; depression; injury such as back pain; high blood pressure, and the deterioration of an existing condition. Carers also report neglecting their own health, or inadequately looking after themselves (missing appointments, delaying treatments and not following healthy lifestyles) because of the demands of caring. The financial demands of caring, particularly if carers have left paid employment or reduced their hours of work due to the needs to provide care, were identified as a further source of stress and worry.

6.60 Similarly, the Carers Trust (Carers Trust, 2016b) has commented that:

“Caring is a risk factor for children and young people’s mental health, which continues to be little understood and often invisible to professionals and policy makers.” (P.4)

6.61 The nature of the relationship in care dyads is one of the mediating factors that can also impact on health and well-being. Confusingly perhaps, closeness of dyadic relationships appears to predict both beneficial *and* adverse carer outcomes. Fauth et al found that closeness between carers and people with dementia is related to better outcomes when viewed cross-sectionally, but poorer outcomes when viewed longitudinally (Fauth, Hess, Piercy, Norton et al., 2012):

“Our findings that higher levels of current closeness predicted declines in affect and mental health for the caregiver and that a greater loss in the relationship (from pre-to post-dementia) predicted poorer physical health over time, together support that poorer relationship quality and loss in the relationship may serve as sources of stress for caregivers, negatively affecting their physical health and psychological well-being.” (P.708)

6.62 Vlachantoni et al's review of care, health and mortality (Vlachantoni, Evandrou, Falkingham, & Robards, 2013) also distinguished between cross-sectional and longitudinal analysis, and drew two key conclusions:

“Firstly, the cross-sectional analysis of data shows mixed associations between informal care provision and poor health outcomes for the carer. Such research highlights the importance of the demographic and socio-economic characteristics of the carer and the person cared for, and of the specific characteristics and nature of the care provided (e.g. duration, level). Secondly, longitudinal analysis, which typically benefits from a longer timeframe to follow up the impact of caring, shows that informal care provision is not per se associated with adverse health and mortality outcomes,

nevertheless particular types and durations of caring have shown negative outcomes.”
(P.114)

- 6.63 As the discussion above has indicated, the impact of caring on carers is multi-dimensional and complex. There is extensive evidence and knowledge – particularly from qualitative exploration – of the ways in which the experience of caring impacts on people’s lives. We have explored how the ‘burden of care’ discourse has evolved and the importance of distinguishing between apparently objective and subjective variables. In unpacking the concept of ‘impact’ we have also paid attention to the positive and valued aspects of caring, and to the variables which appear to influence carers’ capacity to cope and build resilience. At several points in this analysis we have highlighted the difficulties in distinguishing causes from consequences. In addressing the health impact of caring we have examined how the complexities of impact are exemplified.
- 6.64 There are multiple reports and examples of research findings that document carers reporting physical, emotional and psychological impacts of caring. However, there is limited evidence that these are disproportionately experienced by carers relative to people who are not carers. Nonetheless, analysis *has* identified the factors that create greater health risks for carers which are associated with intensity of care, particularly for co-resident carers spouse carers. Such insights are important in informing policy and practice in supporting carers, and particularly in identifying carers who are at greater risk of negative impact, and who are facing the most intense demands, and may require specific interventions to avert crises.
- 6.65 We turn now to consider the review’s findings on support and carers, both in terms of the support needs carers identify, and in their experience of specific interventions and their effectiveness.

7 Scoping the Knowledge: d) Support & Carers

- 7.1 How carers can best be supported is a central question. It was at the heart of the government's 2016 consultation to inform the new Carers Strategy, recognising that carers may need a range of support from services and from the benefits system to enable them to live well whilst caring for someone else. As the charts presented earlier demonstrated, of the four over-arching categories of material identified in the scoping review, support for carers attracted the least attention. While it is important to emphasise that many materials and resources cover more than one category, nonetheless it is true to say that there has been relatively greater attention directed to understanding the nature of caregiving, the characteristics and experiences of carers, and the consequences of caring on their lives, than to examining what makes a difference or which interventions can be judged to be cost-effective.
- 7.2 These are important questions, but in the light of the foregoing analysis it is also evident that this is complex territory; carers are extremely diverse, their experiences have shared but also unique characteristics, and identifying 'what works' oversimplifies the question. However, understanding carers' needs and how best they can be supported are vital objectives that need to be informed by evidence and knowledge.

Carers Needs & Assessment

- 7.3 The importance of addressing carers' needs has been the focus both of national carers strategies and of legislation, culminating in the most recent Care Act 2014. As we outlined in Section 1, the latest legislation consolidates previous legislative requirements and introduces a parity of esteem between carers and service users, strengthening carers' rights to an assessment of need and placing a new duty on local councils to fund support to meet carers' eligible needs, as well as entitling them to relevant information and advice. Support for carers has increasingly come to mean more than recognising carers' existence and helping them to continue caring; it is also about supporting them to live a fulfilled life outside caring, as Larkin and Milne observe, for example (Larkin & Milne, 2013):

"While these have aspired to increase carers' rights across the board, their specific aims are to: improve carers' levels of support; help them to fulfil their educational potential and combine paid work and care; acknowledge their value and importance,

ensure that they are treated with dignity and respect by health and social care professionals; improve their access to information and provide them with opportunities to be involved in service design and delivery as well as professional training.” (P.5)

- 7.4 Nicholas has similarly commented that in attempting to define or assess outcomes for carers, it is essential to appreciate the nature of caregiving, and that traditional concepts of caring (focusing on stress and burden) tended to emphasise relieving strain and preventing breakdown in caring relationships (Nicholas, 2003). However:

“While the difficulties of caring can indeed be considerable, achievement of normal life goals (for example, to work or not, to enjoy a social life), choice and independence are as valid for carers as they are for users of services and arguably offer a more positive framework for measuring outcomes.” (P.33)

- 7.5 Despite the increased attention directed towards assessing carers’ needs, translating this into practice is not straightforward. Take-up of carers’ assessments, for example, has been both low overall and variable between councils. Scourfield suggests that ‘bureaucratic incompetence’ and poor professional awareness might offer part of the explanation, but more fundamentally is the ‘ambiguity’ experienced by professionals dealing with “competing messages and conflicting issues” (Scourfield, 2005).

“Practitioners work in such a maelstrom of competing discourses, for example, users’ rights, carers’ rights, risk, abuse, efficiency, adult protection, independent living, empowerment, partnership and so on, that there is a genuine feeling of confusion and of being deskilled in their work with carers.” (P.26)

- 7.6 Seddon and Robinson have also identified the issue of practitioner ambivalence towards carer assessment *despite* the changing policy and legislative context giving greater recognition and rights to carers (Seddon & Robinson, 2015). They suggest that this ambivalence:

“stems largely from the perceived lack of new types of support for carers following the completion of a separate carer assessment. The continued reliance on traditional social care provision, including home care and respite care, means that practitioners remain cautious about raising carer expectations and identifying support needs, which traditional services do not address. In particular, they are hesitant to discuss the emotional and relational aspects of caring, and explore carers’ associated support needs.” (P.17)

- 7.7 These are important issues because they underline the continuing challenges to translating policy into practice “despite the unprecedented commitment to carer support” achieved in legislative reform and policy aspiration. Seddon and Robinson’s analysis indicates that in part the difficulty lies in user and carer assessment being regarded in practice as unrelated processes, but the conceptual and theoretical progress that has been made in understanding caregiving over the last 25 years, they argue, offer significant insights that need to inform assessment and effective support planning:

“Our findings highlight the need for tools that facilitate a narrative approach to care assessment and provide a platform for carers to reflect on the affective and relational aspects of caring, as well as their future aspirations in and beyond their caring role.”
(P.21)

- 7.8 In our analysis above of the impact of caring, we highlighted the dynamic and complex nature of caring; and the insights that have emerged in conceptualising caring. It would appear that there is a considerable gap in translating this understanding into meaningful carer assessment practice.

- 7.9 The aspirations and expectations of the 2014 Care Act may be considerable. The Government’s own explanation of changes in care and support as a result of the Act state the following:

“Since April 2015, changes to the way care and support is provided in England mean you may be eligible for support, such as a direct payment to spend on the things that make caring easier; or practical support, like arranging for someone to step in when you need a short break. Or you may prefer to be put in touch with local support groups so you have people to talk to.

The council covering the area where the person you care for lives can help you find the right support and you can ask them for a carers’ assessment. A carers’ assessment will look at the different ways that caring affects your life and work out how you can carry on doing the things that are important to you and your family. Your physical, mental and emotional wellbeing will be at the heart of this assessment. As a result, you may be eligible for support from the council, who will also offer you advice and guidance to help you with your caring responsibilities. You can have a carers’ assessment even if the person you care for does not get any help from the council, and they will not need to be assessed.” (Great Britain Department of Health, 2014)

- 7.10 These are, as yet, early days since the legislation, but it is pertinent to ask what difference the Care Act is making to carers' experience. Analysis undertaken by the Carers Trust is not altogether encouraging (Carers Trust, 2016a). For example:

"69% of carers responding to our survey noticed no difference since its introduction and many expressed frustration and anger at the lack of support they received in their caring role. Our survey of carers found that too many carers were unaware of their rights, 65% of carers who responded to our survey had not received assessments under the new Care Act. Our survey made some carers aware of their rights for the first time. The quality of Care Act assessments is cause for concern, 34% of carers responding to our survey felt that their carers' assessment was not helpful." (P.4)

- 7.11 The annual survey of the 'state of caring' undertaken by Carers UK also provides insight to the reality of carers' new rights, particularly in the context of reductions in social care expenditure and widespread pressure on health and care services (Carers UK, 2016)

"The results show that the spirit of the Care Act 2014 and the Children and Families Act 2014 have not become a reality for all – and carers are struggling to get the support from health and care services that they need to care, work and have a life outside caring." (P.5)

- 7.12 31% of carers responding to the survey reported having had an assessment of the impact of caring in the previous year:

"Only a minority of those have an assessment in the last year (35%) were told how to get all the information and advice about their caring role they felt they needed, with 1 in 5 (22%) saying they received little or no helpful information or advice and felt they did not know where to go for support with caring." (P.8)

- 7.13 Carers often experienced considerable delays in getting an assessment, and the experience of those who had an assessment was often poor:

"over half (53%) of carers felt that their ability and willingness to provide care was not properly or insufficiently considered in their assessment or the support they received (...) The area which most carers found was not properly considered as part of the assessment or the support received was the support needed to juggle care with training or education. This was followed by support needed to remain in or return to

work alongside caring – in fact 74% of working age carers did not feel that this was sufficiently considered as part of the assessment.” (P.10)

Interventions to Support Carers

7.14 Increasingly, attention has been directed to examining interventions to support carers and identifying what works, but it is clear that this is a complex issue and evidence is far from conclusive. Services developed specifically to support carers include respite and breaks from caring; at the same time, services provided to support a person needing care (such as home care) may indirectly benefit the carer. In support of the new national Carers Strategy the Department of Health commissioned an economic analysis modelling the implications of unpaid care provision over the next 20 years, and estimating the impact of alternative policy interventions to support carers. At the time of writing, the report had not yet been published (Brimblecombe, Fernandez, Knapp, Rehill, & Wittenberg, 2016).

7.15 Arksey et al reviewed respite services and short term breaks for carers of people with dementia and found the evidence “mixed and at times contradictory” (Arksey, Jackson, Croucher, Weatherly et al., 2004):

“Overall, however, the review found that on the basis of the outcome measures used and on the service that was offered, evidence of the effectiveness and cost-effectiveness of respite care and short-term breaks is limited.” (P.8)

Alongside this, however:

“In contrast, there was considerable qualitative evidence from carers (and some from care recipients) of the perceived benefits of the use of respite services. It would be wrong to assume that lack of evidence of effectiveness should be interpreted as evidence that respite is ineffective.” (P.8)

7.16 In addition to reviewing the literature, Arksey et al also included consultation with national statutory and voluntary bodies and with carers themselves, and the findings from this highlighted the importance of not viewing respite in isolation from wider ‘underpinning factors’:

- Knowledgeable and supportive doctors.
- Appropriate management of the condition.

- Responsive social services.
- Fair and understandable benefits/charging systems.
- Supportive carers' networks.
- Helpful family, friends and neighbours.
- Well-coordinated services.

7.17 Arksey et al comment that the absence of firm conclusions from their review, and the apparent contradictions in some of the findings, point to the complexities of this area, as well as to methodological issues. As they also observe, it may be unrealistic to expect use of respite services to indicate substantial effects for carers, *"especially in the case of those carers who delay the use of services until quite late in the progression of the care recipient's disease"* (P.108).

7.18 Furthermore, specific measures of effectiveness and cost-effectiveness employed in evaluations may be quite different from the subjective perceptions of carers. While there may have been little evidence in measures such as reduced stress, depression or burden, carers nonetheless reported high levels of satisfaction.

"The consultation also suggests that carers see the benefits of respite in quite broad terms which are as much about general quality of life for both carers and care recipients as they are about specific indicators of health." (P.113)

7.19 Conclusions about effectiveness therefore need to address what constitutes effectiveness from the carers' viewpoint as much as from apparently objective measures.

7.20 Mason et al point out that respite care "is not a discrete intervention but encompasses a range of services" intended to provide temporary relief to the carer (Mason, Weatherley, Spilsbury, Golder et al., 2007). Their systematic review examined the effectiveness and cost-effectiveness of different models of community-based respite for frail older people and their caregivers. Their findings were very similar to those of Arksey et al, thus they observed:

"Evidence from this review suggests that respite for caregivers of frail elderly people generally has a small effect upon caregiver burden and caregiver mental and physical health. There is tentative evidence that some caregivers benefit more than others, but caregiver satisfaction levels for all types of respite are generally high, and caregivers appear to be more satisfied with respite than with usual care." (P.297)

7.21 The authors comment that the existing evidence does not allow any firm conclusions about effectiveness or cost-effectiveness to be drawn “and is unable to inform current policy and practice.” They point to the gaps in evidence and the lack of good quality, controlled evaluations for all types of respite care, highlighting the urgent need for robust research.

7.22 Lopez-Hartmann et al’s more recent systematic review focused on the effectiveness of different types of interventions targeting carers of frail elderly people (Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012). The conclusions were similarly cautious:

“Some evidence exists for the effectiveness of respite care, interventions at individual caregiver level, group support and information and communication technology. Overall, the effect of caregiver support interventions is small and also inconsistent between studies.” (P.12)

7.23 Methodological differences, and the use of different outcomes measures and variables make it difficult to compare results between studies.

7.24 Mixed or inconclusive evidence has also been identified for other groups of carers. For example, Arksey et al reviewed the literature on services to support carers of people with mental health problems (Arksey, O'Malley, Baldwin, & Harris, 2002). They found:

“A lack of clear evidence to support any specific interventions, although it is obvious that almost all studies have been able to identify some positive outcomes of services provided.” (P.92)

7.25 In 2010 Parker et al undertook a meta-review of international evidence on interventions to support carers (Parker, Arksey, & Harden, 2010), and updated the analysis in 2016 with the inclusion of sixty one systematic reviews (Thomas, Dalton, Harden, Eastwood, & Parker, 2016). The 2010 meta-review was commissioned by the Department of Health to inform the work of the Standing Commission on Carers, summarising the main findings on support and interventions for carers, and identifying gaps and weaknesses in the evidence base. The strongest evidence of effectiveness was in relation to education, training and information for carers, which were found to increase carers’ knowledge and abilities as carers. However,

*“Beyond this, there is little secure evidence about any of the interventions included in the reviews. We must emphasise that this is **not** the same as saying that these*

interventions have no positive impact. Rather, what we see here is poor quality research, often based on small numbers, testing interventions that have no theoretical 'backbone', with outcome measures that may have little relevance to the recipients of their interventions." (Parker et al, 2010, P.67)

- 7.26 The updated review of 2016 (Thomas et al, 2016) was commissioned by NIHR, and in addition to updating the evidence about how best to support carers given the implementation of the 2014 Care Act, it was hoped that the review might also evaluate interventions such as carer champions, respite care, resilience programmes and health checks. In the event, "of these interventions only respite care has been subject to systematic review to date" (P.90). The findings from the meta-review confirmed that there is no 'one size fits all' intervention to support carers:

"However, what seems clear is that contact with others outside the carers' normal networks (whether professional or other carers) may be beneficial, regardless of how delivered (...) there is potential for effective support in specific groups of carers. This includes shared learning, cognitive reframing, meditation, and computer-delivered psychosocial interventions for carers of people with dementia; psychosocial interventions, art therapy, and counselling for carers of people with cancer. Counselling may also help carers of people with stroke. The effectiveness of respite care remains a paradox, given the apparent conflict between the empirical evidence and views of carers." (P.xx)

- 7.27 The best evidence for interventions "that may have an effect on carers" was defined by the authors as evidence where analysis was based on more than one study, where quality of the primary studies was appraised and reported to be moderate or above for at least two studies, where the intervention type was clearly defined, and where the results of the synthesis were not mixed or inconsistent (P.94). Evidence for interventions that may have a positive effect was identified for carers of people with dementia; carers of people with cancer, and carers helping stroke survivors. These were summarised in these terms:

"For carers of people with dementia:

- *Opportunities to share with and learn from others (whether carers or professionals) may have a positive impact on depression and anxiety, and on subjective burden.*
- *Opportunities to reframe the way they think about dementia may have a positive impact on mental health and subjective burden and stress.*

- *Learning meditation techniques may have a positive impact on depression.*
- *Psychosocial interventions delivered via a computer may have a positive impact on depression and anxiety and on subjective burden and stress.*

For carers of people with cancer:

- *Psychosocial interventions may have a positive impact on carers' physical and psychological 'distress' and quality of life.*
- *Art therapy may have a positive impact on carers' mental health.*
- *Counselling may have a positive impact on relationship functioning.*

For carers of people with stroke:

- *Counselling may have positive impact on family functioning.” (Thomas et al, 2016, P.97).*

7.28 The tentative nature of findings should not come as a surprise. Carers are heterogenous and managing highly individual, complex and demanding situations; it might be expected that effective interventions would be similarly diverse. However, it is also apparent that it remains extremely difficult to disentangle the components of an intervention and to identify the features that are making a difference. As the authors remark:

*“Given the restricted lives some carers lead **any** contact may have beneficial effects. Alternatively, the evidence could reflect the real value of being able to share experiences with and learn from others, whether carers or professionals; but this benefit does appear to be regardless of how the sharing and learning is achieved.” (P.96)*

7.29 Thomas et al emphasise that there remains a dearth of good quality primary research about the effectiveness of most support interventions for carers (and there are particular gaps in the evidence relating to young carers and those from minority groups). This, they believe, reflects the *“lack of underpinning theories of change or intervention logic that would allow the right questions about the right outcomes to be asked”* (P.97). Furthermore, the conundrum of respite care remains with a lack of evidence of effectiveness, and both the meta-reviews found some evidence of negative impact for carers of people with dementia, alongside qualitative evidence indicating that carers attach value to respite care. Thomas et al point to the variability in quality of respite but also to the emergence of new models (including, for example,

memory cafes) which have not been fully evaluated. They conclude that *“primary research that explores what type of respite is better or worse, for whom, and in relation to outcomes that carers themselves think are valuable is urgently needed”* (P.98).

- 7.30 The evidence for interventions that may have an effect on carers is worth exploring here. The main types identified by Thomas et al, and summarised above, were caregiver support groups; telephone counselling; educational programmes; art therapy; meditation-based interventions; computer-mediated interventions; cognitive reframing; couple-based interventions; and psychosocial interventions. Some of the findings of the systematic reviews which informed this conclusion are explored below. It is evident in many cases that findings are inconclusive, contradictory or beset with methodological weaknesses in the original studies.

- 7.31 Chien et al's meta-analysis of professionally-led support groups for caregivers of people with dementia found them to be “significantly effective” (Chien, Chu, Guo, Liao et al., 2011). Educational and psychoeducational groups have different effects:

“This result might suggest that educational groups can immediately provide useful information, such as caregiving skills, ways of self-adjustment, knowledge for handling legal issues, role play, and discussion, and thus facilitate caregivers finding available resources that can reduce their burden in patient care quickly. Psychoeducational groups not only provide practical information on patient care but also focus on caregivers’ psychological and emotional status as well as establishing a social supportive network, and are more effective at improving caregivers’ psychological well-being and depression.” (P.1096)

- 7.32 The distress and burden of caring for someone with dementia have been well rehearsed; interventions that address the psychological needs of these carers are therefore of potential value. Hurley et al identified eight studies of meditation-based interventions for carers of people with dementia (Hurley, Patterson, & Cooley, 2014). The studies demonstrated:

“significant improvements in depression among dementia caregivers, consistent with the application of such interventions to other populations with depression (...) additionally, the interventions have been shown to alleviate burden (...). Consequently, it appears that meditation-based interventions offer a feasible and effective intervention for dementia caregivers experiencing burden or depression.” (P.286)

- 7.33 Longer term follow-up of results suggests that the short-term gains are not always maintained, suggesting that interventions may wish to provide ‘booster’ sessions to support carers in their meditation-based practice.
- 7.34 The review by McKechnie et al focused on psychosocial information and communication technology (ICT) interventions (that is, using DVDs, CD-ROMs, computer programmes or the internet), aimed at both providing carers of people with dementia with information and also improving their wellbeing and coping skills (McKechnie, Barker, & Stott, 2014). Sixteen papers, representing 14 empirical studies, were included in the review. The interventions were “varied and multifaceted, with a range of different outcome measures.” However, most measured impact on carer burden/stress and depression.
- 7.35 The review found the evidence on effectiveness to be mixed but generally positive. However, because interventions were complex and had multiple components, it wasn’t always possible for the authors to disentangle the efficacy of various factors. Limitations in the studies were also a consideration, particularly in terms of poorly defined aims and absence of control groups. Nonetheless, the use of computer-mediated interventions for carers is expanding and McKechnie et al conclude that:
- “it would be beneficial to carers, and also to services – in terms of reaching more carers as well as potential cost saving implications – for this medium of intervention to be developed so that more individuals can benefit.”*
- “More research is, however, needed in order to ensure that interventions are maximally effective. Research needs to consider the effects of interventions on people of different ethnicities and carer-care recipient relationships, as there is evidence that differential effects exist between groups.”* (P.1634)
- 7.36 Although the availability of home computers is continuing to expand rapidly, not everyone has access to such resources, nor to high speed broadband. Some groups of carers (including older carers) are likely to be disadvantaged in having unequal access to, or expertise in the use of technology required for ICT interventions (Carers UK, 2012b)
- 7.37 Marim et al also conducted a systematic review of educational programmes for carers of older people with dementia, but focusing only on randomized controlled trials (Marim, Silva, Taminato, & Barbosa, 2013). They found:

“evidence “to support this type of intervention as being more effective than usual care in reducing the burden of caregivers of patients with dementia.” (P.274)

- 7.38 Waldron et al reviewed psychosocial interventions to improve outcomes for carers of people with cancer (Waldron, Janke, Bechtel, Ramirez, & Cohen, 2013), while Regan et al examined such interventions directed at couples affected by cancer (Regan, Lambert, Girgis, Kelly et al., 2012), and Cheng et al reviewed psychosocial interventions for stroke survivors and their carers (Cheng, Chair, & Chau, 2014). Waldron et al commented that:

“The present findings lend further support to the existing body of literature suggesting that interventions targeting communication and education have an impact on improving caregiver quality of life.” (P.1203)

And

“Overall, the present review suggests that support and education may be the most valued and effective tools for improving caregiver QoL. The largest (although small) effect sizes were for supportive-educational interventions focusing on a wide range of issues including family involvement, optimistic attitude, coping skills, uncertainty reduction, and symptom management. These treatment combinations have not been widely researched within the field of cancer caregiving, and perhaps a combination of support, information, and skills training may achieve significant gains to improve the QoL of adult cancer caregivers.” (P.1206)

- 7.39 Regan et al found the effects of couple-based psychosocial interventions similar to those reported for patient only or carer only interventions, however:

“Couple-based interventions tended to have the greatest impact on improving outcomes such as couple communication, psychological distress, relationship functioning.” (P.9)

- 7.40 The authors conclude that:

“In summary, the findings from this review suggest that there are clear benefits to be gained following the implementation of a couple-based intervention. Although more work is needed, there is enough evidence to be confident that these interventions show promising results in reducing distress and improving coping and adjustment to a cancer diagnosis or to cancer symptoms.” (P.12)

- 7.41 Cheng et al found evidence on the effects of psychosocial interventions for stroke caregivers was limited, and the effectiveness of different types of interventions could not be ascertained because of the limitations of studies available. However:

“There is a trend that psychoeducation, consisting of training in problem solving and stress coping, offered by telephone, reduced the depression level and improved the sense of competency of caregivers, although the summary of the effect was not statistically significant. In addition, equipping caregivers with caregiving skills had a more favourable effect on reducing the use of healthcare resources of stroke survivors.” (P.42).

- 7.42 ‘Cognitive reframing’ refers to a particular element of psychosocial interventions; Vernooij-Dassen et al point out that a key problem for carers of people with dementia lies in understanding and responding to the person’s behaviour, and carers frequently experience anger, anxiety, guilt, depression and other negative emotions as a consequence (Vernooij-Dassen, Draskovic, McCleery, & Downs, 2011). Cognitive reframing can be used as a psychological intervention with carers to identify and modify negative beliefs and interpretations. Reviewing the findings across 11 studies the authors found positive effects over usual care for psychological morbidity (anxiety, depression) and distress, but no effects for coping or self-efficacy, carer burden, reaction to the relative’s behaviour, or institutionalisation. The authors advise that the conclusions should be treated with caution, but suggest that in clinical practice:

“cognitive reframing could be a useful additional tool in individualised support for carers of people with dementia.” (P.11)

- 7.43 The findings by Thomas et al on the possible value of a range of psychosocial interventions to support carers raises the issue of attention to innovative and new models of support more generally, and particularly to models that use RCT methods for evaluation and explore the impact over a sustained period of time. One such intervention worth highlighting is START, not least because it is the first trial to show longer term positive impact. The STrAtegies for RelaTives (START) intervention used a manual-based therapy delivered by supervised psychology graduates without clinical qualifications, and has been described by Knapp et al (Knapp, King, Romeo, Schehl et al., 2013). Coping strategy therapy sessions taught carers techniques to better understand the behaviour of the person with dementia they cared for, to manage behaviour, change unhelpful thoughts, promote acceptance, relax and engage in meaningful activities. Initial evaluation (over an 8 month period) found the intervention

to be cost effective and showed positive outcomes in carers' affective symptoms and quality of life. Knapp et al conclude that:

"An intervention that is cost neutral, even over a relatively short period, and which significantly improves carer mental health and quality of life should be made more widely available." (P.6)

- 7.44 Livingstone et al reported on longer term follow-up which showed similarly positive results (Livingston, Barber, Rapaport, Knapp et al., 2014):

"START (...) improved carers' depression and anxiety symptoms and quality of life not only in the short term, but also up to 24 months later. This is the first trial to show such results." (P.546)

- 7.45 Furthermore, at 2-year follow-up carers in the 'treatment as usual' (TAU) control group:

"were seven times more likely to have clinically significant depression than in the START intervention group." (P.546)

- 7.46 For both groups, social care and care home costs rose over time for the person with dementia as their condition deteriorated. Residential costs increased in both groups, but with a greater increase in TAU than in START "although this result was not statistically significant." Monitoring of the impact on residential admissions is continuing for five years. The conclusions from the evaluation to-date are clear:

"The START intervention is clinically effective in the long term, improving carer mood and quality of life for 2 years. It does not raise costs, and it is cost effective in terms of both carer and patient outcomes with respect to NICE cost thresholds." (P.547)

- 7.47 The authors argue that a cost-neutral intervention such as START "should be made widely available."

- 7.48 In this section of the paper we have provided an overview of the parameters and content of the research and knowledge relating to carers as captured by the scoping review. The state of knowledge on carers is rich, diverse and multi-faceted, and the report has been selective in presenting key themes while acknowledging that there are multiple other dimensions within the knowledge base. At the same time, while we know a lot about the lives, experiences and characteristics of carers, we still are able to offer relatively few conclusions about the evidence of 'what works'. In part this reflects the enormous variability in the carer population and the fact that individual

circumstances can vary in ways that make a difference to resources and outcomes. However, it also reflects the focus of much research around carers to-date, and the need for further work to explore in finer detail what works for which carers and in what circumstances.

8 Conclusions

- 8.1 In this final section we offer some conclusions for policy and practice in relation to carers, and for research. However, we begin by highlighting below the key messages that we have identified throughout the review.

Key Messages

- Knowledge and evidence about carers in the UK and more widely is extensive and varied, and comes from a wide variety of sources including: official government statistics; academic research; and from bodies representing the experiences and voices of carers.
- Caring is extremely diverse and involves all sections and age groups of the population; people are increasingly likely to experience one or more periods of caregiving during a lifetime.
- There are similarities in the experiences of carers but at the same time all caring is unique. All care takes place in a relationship, and every relationship is different, featuring distinctive strengths and weaknesses, positive and negative dimensions, and typically resulting in complex and ambivalent emotions associated with caring, and with identifying 'care' beyond the expectations of a normative activity. Attention to both parties in a dyadic relationship is vital in understanding where interests coincide and where they diverge.
- Knowledge about groups of 'hard to reach' carers remains relatively poor and there are particular deficits in relation to BAME carers and LGBT groups.
- The profile of 'young carers' has grown considerably in recent years as they have attracted the focus of research, but they remain a small proportion of total carers.
- Most care is provided for older people, and typically by adult children or by a spouse/partner. Co-resident carers are the most likely to be spouses or partners and are the most heavily involved in care, while also being more likely to have their own health needs.
- Older carers continue to be relatively invisible in policy, practice and research and are less likely to identify themselves as carers because of the context of their

relationship which is characterised by long-term reciprocity, mutuality and interdependence.

- There are newly emerging 'sandwich care' generation issues: adult child carers providing most intensive support (at least 20 hours a week) are aged under 65 and typically juggling the demands of caring and paid employment. Evidence indicates that a third of women aged 55-69 are providing care to both younger and older generations – reflecting the extension of dependency of adolescents/young adults and their economic dependence on parents.
- Just as carers are diverse, so the nature of their caring situation varies, but the most frequently identified themes in the evidence and knowledge are concerned with older people and dementia. Mental health – both in supporting people with mental health needs, and the mental health of carers – attracts considerable attention, and the tensions and contradictions in the caring role are particular considerations here.
- The impact of caring covers a wide range of themes – from abuse and care, through conflict in caring, ethical issues, risks and resilience and stress and strain. Every aspect of life can be impacted by caring. Much research and associated narrative has adopted a 'burden of care' discourse focusing on the negative consequences of caring, but this language is highly pejorative and one dimensional and needs to be seen alongside the satisfactions and intrinsic benefits of caring. This is not to promote a rose-tinted view of caring, but to acknowledge the complexity and multiple dimensions that need to be recognised as co-existing within caring relationships and interdependencies.
- How carers cope – and how they can be taught appropriate coping strategies - is also attracting more attention and results are promising in terms of improved wellbeing for carers, although the impact on people being supported may be less evident.
- Increasing attention is being directed to balancing the demands of work, life and caring, and supporting working carers is a recurrent policy theme. Around half of all carers are in paid employment, and caring responsibilities are a major reason for premature withdrawal from the labour market (particularly for women). The business case for employers to support carers is one that has been made, but it is a complex territory without any quick fix and flexibility may not be offered to carers

in low paid, or low skilled work compared with those in more professional and managerial roles. Equally, focusing on supporting working age carers is of no benefit to many of the most heavily committed carers who are elderly and retired.

- Much of what we know about carers is about their characteristics; their lives, and the nature and duration of the care they give, and less is known about interventions that support carers in general and specifically which ‘work’ for which carers. However, ***lack of evidence of effectiveness is not evidence of ineffectiveness***.
- Evidence about what services and support can benefit carers is equivocal and some of the findings – such as on respite care – are contradictory. Psychosocial interventions appear to have the best evidence of making a difference for some carers (notably for carers of people with dementia, with cancer, and those who have had a stroke).
- There is not a quick fix or a one-size-fits-all model, so support has to be tailored, and sometimes it is *the process* of support and interventions that may be valued even if the end outcomes do not indicate positive effects – what is being measured, and whether the measures are most appropriate needs to be considered. However, assessment of effectiveness must address the dyadic context in which care takes place; without attention to both sides there are risks that any conclusions are distorted or risk causing negative unintended consequences.
- There is a great deal of knowledge on a vast array of subjects under the ‘carer umbrella’. That knowledge comes from a wide range of sources – from theoretical and conceptual models; from professional practice development, and - most importantly – from the voices and lived experience of carers.
- Providing the overview of evidence and knowledge enables us to go from the big picture to the small and to maximise the value of the cumulative weight of knowledge. It is important to keep sight of all aspects of caring and not to ‘salami slice’ care or focus disproportionately on sub-groups to the detriment of others.

Implications for Policy, Practice & Research

- 8.2 As we explored at the beginning of the report, the objectives of the review were two-fold; both to map carer-related knowledge and evidence, but also to create a resource that would be accessible, useable and dynamic in order to inform a wide range of carer-

interested parties. We believe there is considerable value in having undertaken this unique review; and that for the first time this offers a report and associated data resource that will be of benefit to a wide range of audiences seeking information and knowledge on different aspects of carers and caring.

- 8.3 However, the resource is not an oracle and will not provide simple solutions for policy makers or practitioners wanting to identify short-cuts or easy answers to caring dilemmas. There is no single panacea, but there are multiple areas in which knowledge of carers' experiences and of *what makes a difference to them*, can and should inform policy and practice. Moreover, the current state of knowledge is able to identify critical pinch points and to highlight groups (and sub-groups) of carers that are likely to be under particular strain and pressure and where attention should be prioritised.
- 8.4 As we have explored, the factors that may make the most difference to carers, and those they care for, may not be the standard service 'offer'. Evidence on respite services, for example, is at best equivocal, but breaks from care are generally valued by carers. Building carers' resilience and enabling them to develop strategies to manage the stress and pressure they experience appears to be an important area to develop further. At the same time, this cannot be an excuse for failing to provide practical help and support, and these two components need to be developed in parallel.
- 8.5 For the research community, and those that commission research, there are also some important conclusions. It is illuminating to reflect on the *nature* of the evidence base and knowledge about carers. Milne and Larkin have previously identified the bifurcated nature of carer-related knowledge, with two separate and distinctive paradigms, namely 'Gathering and Evaluating', and 'Conceptualising and Theorising' (Milne & Larkin, 2015). Their analysis indicated that the former paradigm,

"is closely aligned to the dominant discourse about caring in the UK and primarily focuses on profiling the nature and extent of care-giving, assessing its impact and evaluating the effectiveness of carer-related policy and services." (P.5)

- 8.6 As this scoping review has also demonstrated, much of the carer-related knowledge is focused on: describing and quantifying the carer population profile in terms of numbers and characteristics; documenting the impact and sequela of care-giving within a 'burden of care' narrative, and – to a lesser extent – evaluating support for carers,

usually within relatively narrow cost-effectiveness parameters of 'what works' in enabling carers to continue caring.

- 8.7 Milne and Larkin's second paradigm of 'conceptualising and theorising' focuses on:

"the conceptual and experiential nature of care; it aims to extend thinking and theory about caring as a multidimensional activity and as an integral part of human relationships." (P. 6/7)

- 8.8 As we acknowledged in Section 1, while the term 'carer' is in widespread use and generally understood in popular, research and policy discourse, it is not universally embraced or owned, even by many putative carers for whom it is integral to the nature of a dyadic relationship. Furthermore, the appropriateness of the term is to some extent at least contested, not least because of the complexity of inter-dependency and reciprocity within relationships which render the carer/cared for distinction as a false dichotomy.

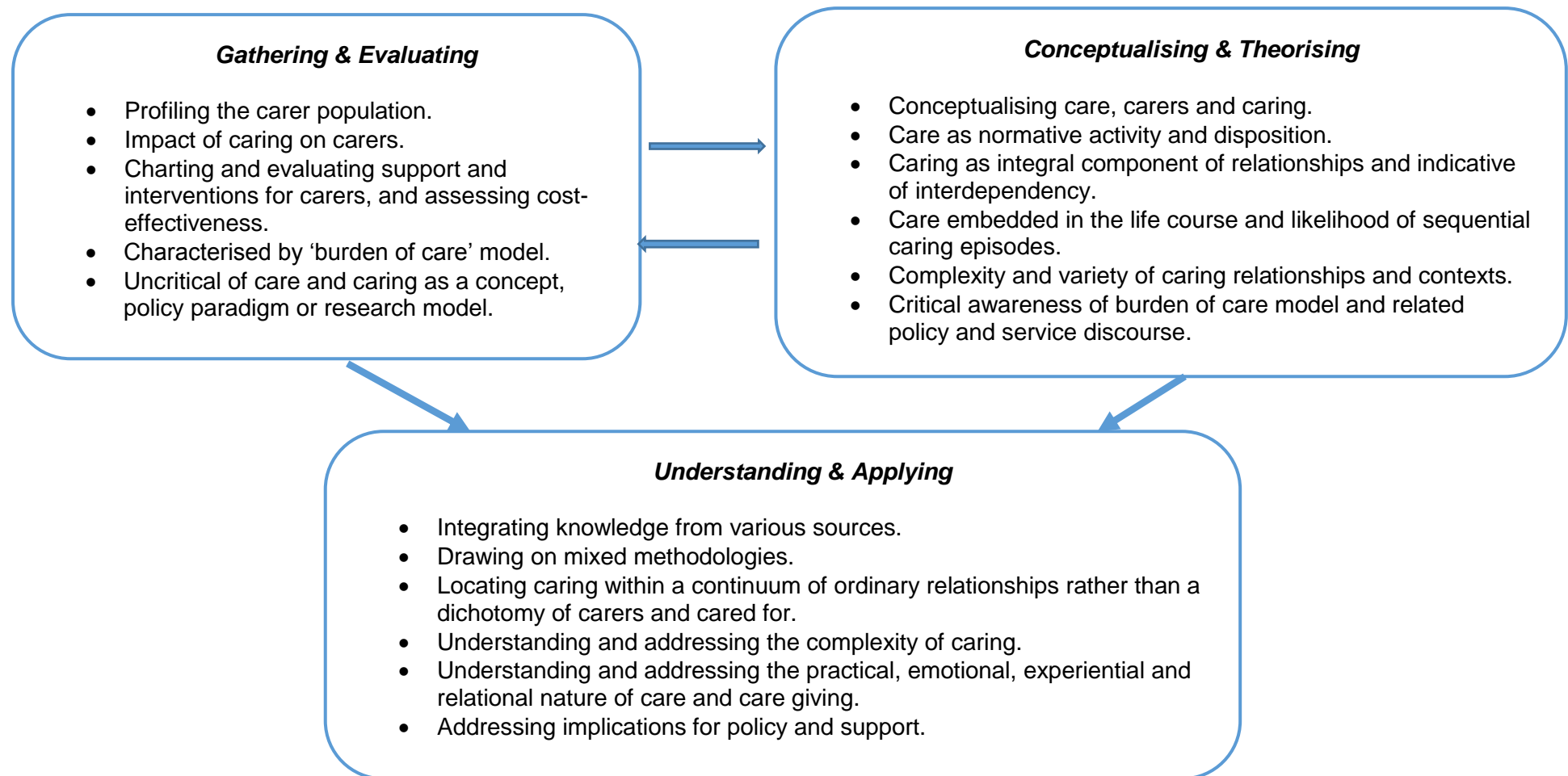
- 8.9 Milne and Larkin's conclusion that there are two separate research paradigms operating in carer-related knowledge, which have different perspectives and approaches, finds considerable traction and resonance within the current review. As we have described and discussed, there is no shortage of knowledge and research about carers, but the overall contribution may indeed be less than the sum of the parts, and certainly less than it could be with appropriate synergies exploited and greater awareness and understanding of the respective contributions of different approaches. Figure 8.1 outlines an integrated research and knowledge paradigm under the title of 'Understanding and Applying'. This model seeks to bring together the features and distinctive components of the two dominant paradigms which have tended to be in some tension if not diametrically opposed.

- 8.10 This is of more than academic importance. Indeed, it is central to the conceptual understanding of carers and caring within the health and social care system. In Section 1 we explored the tensions and contradictions that have existed in the development both of research and in the underlying assumptions informing policy and practice. The implementation of the 2014 Care Act does not remove these challenges, and arguably the introduction of 'parity of esteem' for carers once again raises the issue of balancing the interests and choices of carers with those of people with disabilities or support needs. Failure to address this explicitly, or to assume that the interests always coincide, does not recognise the complexity and inter-connectivity of caring

relationships for either party. The assumptions, beliefs and understandings about carers and caring that underpin policy in social care generally, and carers strategies in particular, need to be made transparent. As Arksey and Glendinning have pointed out (Arksey & Glendinning, 2007):

“This would mean that the common and separate choices and interests of both carers and the people cared for are not neglected (...) By incorporating support to both carers and care recipients, policy measures have the potential to facilitate increased choice for both groups.” (P.173)

Fig. 8.1: Towards an integrated research & knowledge paradigm



- 8.11 We can see the present review as one attempt to locate itself within an integrated paradigm. In place of the frequently fragmented and partial nature of research and evidence, we have sought to identify and understand knowledge drawn from a wide range of sources and approaches. We have not attempted to classify material along a hierarchy, nor to assess the quality of individual studies. We have also rejected adopting the dominant narrative of much research which typically addresses caring outwith the context of any relationship, and which risks constructing carers' needs in a separate and simplified manner that may be antagonistic to the needs of those they care for. Instead, our integrated paradigm has sought to illuminate the complexity of knowledge about care and caring and to understand the interdependencies and counterpoints inherent in relationships.
- 8.12 It is of ongoing importance that the state of knowledge about carers and their lived experience should be maintained and extended. It is also crucial to address the deficits in existing knowledge and to direct attention towards expanding the evidence base, while recognising that such evidence comes in many forms.
- 8.13 Finally, a major shortcoming in much of the research – and one that is repeatedly identified by academics – is the reliance on cross-sectional evidence because of the absence of longitudinal datasets (with some minor exceptions). The need to examine the impact and experience of caring over time, and the nature of caring through the life cycle has long been recognised, and the capacity to do so would be much enhanced by the availability of robust longitudinal data.
- 8.14 This review has, for the first time, used a scoping methodology to identify and classify the wide and diverse carer-related knowledge base. We do not claim to offer a definitive or final overview of this territory, since by its nature it is dynamic and evolving. However, we have created a unique foundation for a resource that can be expanded and developed and which lends itself to further analysis and exploration.

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Appendix 1: Bibliographic Sources

Overview

This appendix draws together the 3,434 items that were identified in the scoping review. It classifies them into 17 types of reference for ease of identification, and these are organised alphabetically.

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